An Exploratory Study into the Factors that Constrain or Enable Voluntary HIV Testing Among Young Adults in Cape Town, South Africa

Hannah Lane / LNXHAN001

A minor dissertation submitted in *partial fulfillment* of the requirements for the award of the degree of

MPhil in HIV/AIDS and Society

Faculty of the Humanities

University of Cape Town

2008

COMPULSORY DECLARATION

This work has not been previously submitted in whole, or in part, for the award of any degree. It is my own work. Each significant contribution to, and quotation in, this dissertation from the work, or works, of other people has been attributed, and has been cited and referenced.

Signature: _____ Date: 2/6/08

Acknowledgements

I am thankful for my life and the people who have contributed to the making of this thesis. Those who prepared me for a life of activism, who introduced me to South Africa, and who added to my understanding of health and well-being. I am thankful to those who I do not know but who are also committed to these causes; we are all in this together. I am thankful to those who have shared with me their stories, boldly and brazenly, and who want – with me – to better the world.

The writing of this thesis would absolutely not have been possible without the amazing people who I am so very lucky to have in my life. To my partner and my friends and my supervisors and my family who remind me what an accomplishment this is and also how much more I have to be grateful for. The patience and encouragement I have received from all of you has been invaluable and I am alive and well today because of your faith in me. Each of you has held me in my greatness and awaited my arrival with endless joy.

A toast! To late nights and long talks and car rides and warm tea. To reading, re-reading, you reading, and time. To chats about cats, countries, struggles, and life. To living, just living, and loving and giving. To broken PCs and hand written lists, late library books and early morning oats. To tomato soup and toasted nuts and green cup cakes and packed lunch packs. To future dreams and grounded goals, to far away places and trucks for long hikes. To bubbles, pink bubbles, and 10-year-old wine. To lending books and sharing thoughts and inner tubes and laughing goats! From there to here, from me to me to who? To grace and support and faith in the process. Thank you.

Figure 0: FINISHED!

Abstract

Despite exceptionally high HIV prevalence rates, South Africa experiences prohibitively low levels of HIV testing. Considered to be a key element in the prevention of HIV transmission and a necessary gateway for providing care and treatment for those who are infected, widespread ignorance of HIV status has become a mounting concern in countries with high prevalence rates. Strategies for increasing testing rates have most commonly focused on testing and treatment services, such as the availability and accessibility of clinics offering voluntary counselling and testing (VCT), the number of trained nurses and health practitioners able to administer HIV tests, the possibility of instituting routine HIV testing to increase coverage, and the provision of highly active antiretroviral treatment (HAART) in the event of a positive diagnosis. These efforts seek to either increase access to testing through infrastructural improvements or encourage testing by highlighting its function as a gateway to accessing medical services to manage HIV infection and future transmission. In a departure from these strategies, this thesis considers the physical, social, and psychological ramifications of living with HIV – and not simply issues of access, treatment, and prevention – in order to understand HIV testing practices.

Qualitative in-depth interviews were conducted with 15 young adults (6 male and 9 female) living in Cape Town, South Africa. Semi-structured in-depth interviews collected information about: 1) knowledge and sources of knowledge about HIV/AIDS, as well as how this knowledge changes over time; 2) beliefs and attitudes towards HIV and HIV testing, including corresponding health-seeking behaviours; 3) personal stories about HIV testing, including reasons for and reactions to testing; and 4) possible strategies to encourage HIV testing in the future.

Study participants identified three broad threats that were perceived to be experienced by HIV positive people and explained how the HIV test served to either mitigate or expose an individual to these threats. Physical threats posed by HIV, such as opportunistic infections or death, encouraged HIV testing as it was only through testing that these potential threats could be mitigated. Conversely, an HIV test exposed an individual to social and psychological threats. The social threats of living with HIV included exclusion, rejection by family and friends, and social shame. Psychological threats included mental destruction, depression, and stress, among others. Where social and psychological threats were perceived to be strong, testing was actively avoided.

The findings of this study are that the decision to voluntarily test for HIV can be explained through a balance of the physical, social, and psychological threats that may be managed or catalysed through an HIV test. When study participants perceived physical threats to outweigh perceived social and psychological threats of living with HIV, they were biased towards testing. When they viewed social and psychological threats to outweigh physical threats, they were biased against testing. This focus on the perceived threats of living with HIV highlights the need to have a comprehensive approach to AIDS and HIV, rather than merely focusing on the clinical diagnosis and treatment of symptoms; enhanced infrastructural resources and the opportunity for mitigation of the physical threats alone do not encourage HIV testing.

Glossary of Acronyms

ABCs – Abstain, Be Faithful, Wear a Condom

AIDS – Acquired Immune Deficiency Syndrome

ANC – African National Congress

ART – Antiretroviral Therapy

ARVs – Antiretrovirals

DoH – Department of Health

HAART – Highly Active Antiretroviral Therapy

HBM – Health-Belief Model

HIV – Human Immunodeficiency Virus

HSRC – Human Sciences Research Council

MSF – Médecins Sans Frontières

NGOs – Non-governmental organisations

NSP – HIV & AIDS and STIs National Strategic Plan

OIs – Opportunistic Infections

PBC – Perceived Behavioural Control

PITC – Provider-Initiated Testing and Counselling

PMTCT – Prevention of Mother-to-Child Transmission

RCT – Routine Counselling and Testing

SANAC – South African National AIDS Council

SHAWCO – Students Health and Welfare Organisation

SRT – Social Representations Theory

STDs/STIs – Sexually Transmitted Diseases/Infections

TAC – Treatment Action Campaign

TB – Tuberculosis

UNAIDS – Joint United Nations Programme on AIDS

VCT – Voluntary Counselling and Testing

WHO – World Health Organisation

Table of Contents

Your state of health – the term of your life – is a matter of deepest privacy, most integral to your conception of your life and being. It is part of what defines hope and expectation. It has been said that what distinguishes humans from other animals is our conscious apprehension of mortality. That sense – its translation into present knowledge – must always be approached, addressed, its imminence determined and imparted with utmost veneration (Cameron 2005:50).

Chapter 1 – Introduction

HIV/AIDS has imprinted so heavily on South Africa that beaded trinkets sold at daily "African" markets as holiday souvenirs depict the AIDS ribbon beneath a South African flag, undeniably cementing their indivisibility. The HIV statistics in South Africa have risen and remained high ever since the virus took hold in the general population in the early 1990s (Iliffe 2006:43). National estimates from 2005 predict an HIV prevalence rate of 10.8% in the population 2 years and older (Shisana, et al. 2005:33) and 18.8% in the adult (15-49) population (SANAC 2007:7). UNAIDS estimates show that 5.5 million people are living with HIV in South Africa and that in 2006, an estimated 320,000 people died due to AIDS (UNAIDS 2006b:11; UNAIDS 2006a:445). This brings the total deaths due to AIDS to over 1.8 million (Dorrington, Johnson, Bradshaw, and Daniel 2006:20). These numbers place South Africa at the top of the list for having the largest HIV-infected population in the world. Furthermore, at the tip of sub-Saharan Africa, South Africa is located within the most affected region in the world, surpassing the next hardest-hit region (South and South-East Asia) by nearly 18 million people estimated to be living with HIV (UNAIDS 2007:39)[1].

Despite these high prevalence rates and AIDS-related deaths, less than 1 in 3 people in the South African population of 47 million have ever been tested for HIV (Shisana, et al. 2005:80). This means that in a country with an exceptionally high HIV prevalence rate, 70% of people are naive to their status, 2 million of which are estimated to be unknowingly HIV-positive (UNAIDS 2006b:13). Low levels of testing pose particular challenges in stemming the growth of the epidemic and caring for those who have been infected with the virus. Indeed, there is growing awareness that "among the interventions which play a pivotal role both in treatment and prevention, HIV testing and counselling stands out as paramount" (UNAIDS/WHO 2004:1). In an unprecedented collaboration between civil

[1] Without a more careful examination, these statistics are useful merely for expressing the dramatically uneven distribution of HIV/AIDS across the globe and highlight the especially affected country of South Africa. They do not express the vast differences within the country, across regional, gender, and economic lines, nor do they explain why these differences exist. Although the complexity of acquiring such statistics makes their value tentative, it can be argued that pinpoint accuracy is not necessary to discern that there is a problem.

society organisations, AIDS activists, academics, the international community, and select government officials, South Africa has made increasing the uptake of voluntary HIV testing a key priority in its newly drafted HIV & AIDS and STIs National Strategic Plan (NSP) 2007-2011 (SANAC 2007:16). However, while the physical threat that HIV poses to both those infected and uninfected with the virus is well established, the circumstances that provoke some people to "prefer death over testing" (Mgcobo 2007) are less explored and are consequently silently noxious. It is thus important to conduct an investigation into the reasons why so few South Africans have been tested for HIV.

A number of factors have been used to explain why more people have not been tested for HIV. These factors include a lack of access to testing services, a lack of knowledge about AIDS, a lack of appropriate treatment and care for HIV positive people, and high levels of HIV-related stigma (Asante 2006; De Cock, Mbori-Ngacha, and Marum 2002; Gilmore and Somerville 1994; Goffman 1963; Kalichman and Simbayi 2006; Nattrass 2003; Nattrass 2007; Sontag 1978; Sontag 1987). As HIV testing has been identified as a key element in HIV prevention and is necessary for providing in-roads for the treatment and care of HIV positive people, new insights on these and other barriers are needed in order to develop strategies that will increase the rates of HIV testing and help achieve the subsequent goals of prevention and treatment initiatives. Two methods of HIV testing, specifically client-initiated testing and counselling (sometimes called voluntary counselling and testing, or VCT) and provider-initiated testing and counselling (PITC), have been at the forefront of the discussion on how to increase rates of HIV testing. These two testing methods have also been central to the debate of whether HIV testing is a human rights or a public health issue.

In revisions to the clinical diagnosis of a disease, calls are often made for expanded "biopsychosocial" understandings of illness (Engel 1977). Viewing HIV/AIDS as an illness rather than a clinical disease, this study explored the biological, psychological, and social elements of HIV testing. This study finds that a shift away from the testing process and the biomedical justification for its use was necessary to understand testing behaviour. Instead of merely a response to biological knowledge about HIV/AIDS or ARV treatment, both of which are believed to encourage early testing and diagnosis, HIV testing practices can also be linked to the biological, psychological, and social experience of living with AIDS or HIV.

This thesis describes the findings of an exploratory study that set out to uncover the determinants of the low levels of HIV testing in South Africa. Through qualitative in-depth interviews with 15 young adults from Cape Town, South Africa, this study found that choices surrounding HIV testing were strongly linked to the perceived outcome of the HIV test. Moreover, the perceived threats posed on

those who were HIV positive, namely physical threats, social threats, and psychological threats, either encouraged or discouraged testing.

1.1 Chapter Synopses

Chapter 2 reaffirms the importance of increasing levels of HIV testing in South Africa by showing that both prevention and treatment interventions will benefit from more people knowing their HIV status. It contextualises HIV testing by reviewing past research on barriers to testing as well as suggested strategies to increase testing by changing the model for testing from a client-initiated to provider-initiated approach. It also highlights how HIV testing cannot be divorced from the consequences (both positive and negative) that may result from a positive test result. A biopsychosocial approach to living with HIV is necessary for understanding a practice that may confirm one's HIV positive status. Chapter 3 explains the methodology for this empirically based study. Chapter 4 outlines three threats that were perceived to be consequences of living with HIV, as defined by the research participants. It also explains the relationship that each of these threats has to HIV testing. Chapter 5 proposes a model for understanding the relationship between physical, social, and psychological threats. Using case studies of participants' testing experiences, this chapter demonstrates that a bias towards HIV testing can be understood as point at which physical threats (which may be mitigated through testing) outweigh social and psychological threats (which one may be exposed to through HIV testing) in the event of a positive HIV test result. Chapter 6 will conclude the thesis by reviewing the findings of the study and offering suggestions for future interventions.

Chapter 2 – Motivation and Conceptual Framework

2.1 Introduction

This chapter provides a motivation for the study and extends the rationale for investigating the determinants of low levels of HIV testing in Cape Town, South Africa throughout the subsequent conceptual framework. It also provides a theoretical framework for understanding a biopsychosocial approach to health, disease, and illness, which will be used to frame the empirical data and subsequent analysis. The background for this study begins with an overview of HIV testing by discussing its proposed benefits, namely that it can provide an opportunity for care and treatment for those who are positive and that increased levels of HIV testing, if accompanied by counselling, may lead to HIV prevention (Hutchinson and Mahlalela 2006; Pronyk, Kim, et al. 2002; Sweat, Gregorich, et al. 2000; UNAIDS/WHO 2004; Voluntary HIV-1 Counseling and Testing Efficacy Study Group 2000; Weiser, Heisler, et al. 2006). This will help bolster the need to better understand factors that will lead to an increase in the uptake of HIV testing.

The next section will place this research in a larger historical debate that has pitted HIV testing as a voluntary function of an individual's human health rights against the view that routine testing is a necessity for maintaining the public's health and well-being (DeCock 2005; Heywood 2005; Kenyon 2005; Macklin 2005; Tarantolla 2005). The distinction between testing as a human rights or public health issue is useful when understanding the largely client-initiated nature of HIV testing in South Africa, and the implications this has on individual choice and responsibility around health.

Third, an investigation into possible explanations for low levels of HIV testing in South Africa reveals that limited access to testing services, low perceived knowledge about HIV/AIDS and testing services, links between HIV and death, and high levels of HIV-related stigma are some factors that have been used to explain low levels of voluntary testing (Asante 2006; De Cock, Mbori-Ngacha, and Marum 2002; Gilmore and Somerville 1994; Goffman 1963; Kalichman and Simbayi 2006; Nattrass 2003; Nattrass 2007; Sontag 1978; Sontag 1987; UNAIDS Reference Group 2005). Using examples from other countries, as well as research done in South Africa, these barriers to testing will be evaluated in order to give way for new insights that may improve uptake of HIV testing.

The fourth section will look further at the evolution of two particular testing methods which lay at the core of the human rights/public health debate, namely client-initiated testing and counselling

and provider-initiated testing and counselling. Arguments have been made both for and against each method with regards to the opportunities they provide for increasing uptake of HIV testing. Highlighted in the arguments will be the potential role these testing methods have on overcoming the barriers to testing that were discussed in the previous section. The argument over testing methods, and ultimately the value of HIV testing, will be critiqued in empirical Chapters 4 and 5, which explain that even when uptake of HIV testing increases, the ultimate goals of achieving HIV prevention and expanded treatment coverage may not be addressed.

In order to understand why neither testing method fully addresses the goals of treatment and prevention, this thesis draws on the biopsychosocial model for health and distinguishes between disease and illness in order to understand HIV testing behaviour (Engel 1977; Helman 1981, Kleinman 1980). This model will be drawn on in Chapters 4 and 5, where focus will be placed on the consequences of a positive HIV test result and the impact this has on choices around testing.

2.2 Motivation for study: Testing as treatment and prevention

Antiretroviral drugs for the treatment of opportunistic infections in the advanced stages of AIDS form a crucial part of the response to the AIDS epidemic. ARVs have the potential to improve the health and lives of HIV-positive people dramatically. By reducing levels of the HI-virus in the body and allowing the immune system to rebuild, ARVs prolong life and can transform AIDS into a chronic rather than a fatal illness (Abadía-Barrero and Castro 2006:1226). Knowledge of HIV status is a precursor for the commencement of antiretroviral treatment and care associated with AIDS-related sicknesses (Hutchinson and Mahlalela 2006; UNAIDS 2004). With a large portion of the South African population unaware of their status, low levels of HIV testing create a significant barrier to the health and well-being of millions of HIV-positive individuals. As highly active antiretroviral therapy (HAART) for the treatment of HIV becomes increasingly available in South African public hospitals and clinics, a similar increase in the uptake of HIV testing is also necessary before ARVs can be accessed and their benefits can be realised. While an HIV test does not guarantee either access to nor uptake of antiretroviral treatment, knowledge of status is a necessary prerequisite if HAART is to be initiated.

In addition to enabling access to treatment, HIV testing may also contribute to HIV prevention (Sweat, Gregorich, et al. 2000; Weiser, Heisler, et al. 2006). One key instance where testing may have such results is for the prevention of vertical transmission, in other words the transmission of HIV from a pregnant mother to her child (MTCT). With the use of ARVs during the last stages of

pregnancy, the chances that a pregnant mother will transmit HIV to her child are greatly reduced[2]. Aside from this form of prevention, HIV testing is also believed to lower the incidence of horizontal transmission of HIV[3] from HIV positive individuals to their HIV negative sexual partners. In many instances, "testing and knowledge of one's HIV status are important because a positive HIV test could activate behaviour modification that may reduce the risk of onward transmission" (Asante 2007:644). The suggestion that testing could contribute to HIV prevention is predicated on the belief that the counselling services that accompany the HIV test encourage individuals to change their sexual behaviour practices. A commonly cited study conducted by the Voluntary HIV-1 Counseling and Testing Efficacy Study Group found that the VCT provided the "opportunity for education and behaviour change" and that knowledge of one's status was crucial in allowing "individuals to plan, make important life decisions, and seek care and support" (2000:103). This study, done in Kenya, Tanzania, and Trinidad, used the first randomised trial to test the efficacy of VCT in reducing transmission of HIV. Compared to basic health information provided at the time of the test, voluntary counselling and testing[4] was more effective in encouraging individuals to have protected sexual intercourse and reduce the number of non-primary partners (Voluntary HIV-1 Counseling and Testing Efficacy Study Group 2000: 107). Thus, HIV prevention through the promotion of abstinence, being faithful to one's partner, and condom usage (ABCs[5]) is enhanced when comprehensive counselling accompanies an HIV test[6].

As previously stated, South Africa has prohibitively low levels of HIV testing. With adult (15-49) HIV prevalence rates topping 18% in South Africa (SANAC 2007:7), the prospect that HIV testing can stem further growth of the epidemic and provide in-roads for care makes this research, exploring the conditions for such low testing rates, absolutely critical.

---

[2] Prevention for MTCT of HIV in South Africa relies heavily on routine testing of pregnant women.

[3] In South Africa, the mode of HIV transmission is almost exclusively through sexual intercourse, and almost always between and a man and a woman (Abdool Karim 2005).

[4] VCT was characterised as "personalised risk assessment [and] development of a personalised risk reduction plan for each client" (Voluntary HIV-1 Counseling and Testing Efficacy Study Group 2000:104).

[5] The efficacy of ABCs for the prevention of HIV transmission has been problematised in literature which adopts a gendered perspective on the AIDS epidemic (Abdool Karim 2005; Farmer 2001; Farmer 1996). In particular, women living in poverty have less control over their own sexual health and are less able to enforce condom usage, monogamous in relationships, and abstinence with their male sexual partners.

[6] In contrast to these findings, other studies have found that HIV testing may only lead to behaviour change and HIV prevention for those individuals who test HIV positive, and more often, there is no change in sexual behaviour following an HIV test (Glick 2005; Kippax 2006). Indeed, the link between increased HIV-related knowledge and sexual behaviour change is problematic and is discussed in detail later in this. Space restrictions do not allow for a full discussion about the link between HIV testing and prevention outcomes.

2.3 Debates around HIV testing

2.3.1 HIV testing: Public Health or Human Right?

HIV testing has a long history rooted in a debate between human rights and public health. This debate is primarily concerned with different methods of HIV testing and balances an individual's rights to autonomy in health care decisions against the health benefits of the greater society. Present since the beginning of the epidemic in the 1980s, this debate has resurfaced in the advent of expanded antiretroviral therapy where increasing HIV testing has renewed importance for scaling up HAART coverage.

Jonathan Mann, founder and former head of the Global AIDS Programme on HIV/AIDS at the WHO, decided in the late 1980s that everyone should be afforded the choice of whether or not they wanted to be tested for HIV. He made HIV testing a voluntary practice because he was anticipating the massive stigmatisation that comes with an HIV-positive diagnosis (PBS Frontline 2007). In the early stages of the epidemic in the United States before the advent of HAART, a positive diagnosis was met with few options for care or treatment and so a heavy push to identify infected individuals was likely to further ostracise and alienate the already marginalised groups to which the virus was associated (homosexuals, injecting-drug users, commercial sex workers, etc.). Thus, rather than activate participation in prevention measures, many feared that a witch-hunt would actually discourage acknowledgment of the virus (Bayer and Fairchild, 2006). Because of this association with already marginalised groups, Mann wanted to safeguard against the discrimination and potential violence that mandatory HIV testing might bring and instead chose to protect human rights by providing patients with control over their own health care decisions. Revered for his strong belief in protecting individual freedoms and providing health care for every citizen of the world, Mann prioritised the individual over the group, arguing that violating human rights was not acceptable at any cost (Mann, et al. 1999). Born out of this line of thinking was the VCT method of HIV diagnosis.

Recent evaluations of the epidemic in Africa have argued that this early approach is part of the cause for such high prevalence rates across the continent (De Cock, et al. 2002); the public's health has been compromised at the expense of protecting human rights. Encouraging privacy and personal choice around testing has led to "HIV exceptionalism." Rather than treating HIV like other infectious diseases, "for which consent for testing is implicitly assumed by virtue of medical consultation, and diagnosis is encouraged, the diagnosis for HIV infection has often been actively avoided" (De Cock, et al. 2002:68). Much like the early responses to HIV testing and diagnosis that were practiced in the West, when the epidemic was being addressed in African countries, a similar human rights approach

was adopted. In hindsight, the high infection rates across sub-Saharan Africa are often attributed to the low priority given to tracking and containing the virus, as is standard with other infectious diseases such as TB, syphilis, and hepatitis B (De Cock, et al. 2002:68). Furthermore, proponents of a public health approach to HIV testing would argue that

> The emphasis that has been placed on anonymity for HIV-infected people, which is different from confidentiality and analogous to secrecy, might also have been counterproductive. Anonymity is impossible to maintain as immune deficiency progresses. The quest for secrecy promotes rather than breaks the destructive silence around HIV/AIDS, and divides the known infected from the undiagnosed and uninfected (De Cock, et al. 2002:69).

Rather than protect individuals, exceptionalisation of HIV through making HIV testing voluntary rather than routine (and thus normalised) is thought to lead to increased fear, stigma, and blame because the virus has been viewed as something that should remain hidden. De Cock (2002; 2005), among others, thus advocates a method of routine counselling and testing (RCT). Of the four different types of testing policies identified by UNAIDS/WHO in 2004, namely mandatory testing, voluntary counselling and testing, routine counselling and testing, and diagnostic testing, two methods (VCT and RCT) characterise this discussion of humans rights and public health. These two testing methods have subsequently been revised (WHO/UNAIDS 2007), and can now be conceptualised as client-initiated and provider-initiated testing and counselling. However, much of the literature still uses the terms VCT and RCT to describe these two methods of HIV testing and this is reflected in this thesis.

Representing the core of the human rights position, client-initiated testing and counselling (or VCT[7]) relies on patients who are accessing health services to specifically request an HIV test. Currently practiced in most countries in sub-Saharan Africa as well as the majority of the rest of the world, this method is prefaced and followed by counselling sessions, both of which allow patients to ask questions and allow counsellors to educate patients about risky behaviours and ways to prevent transmission of the virus. Client-initiated HIV testing is often supported by the argument that "to impose any biomedical test on people without their explicit, informed consent amounts to a restriction of rights" (Tarantola 2005:37). This form of testing is also cognisant of the fact that ARV treatment is not always available and accessible, making a policy of routine testing unethical.

> The major benefit to individuals' learning that they are HIV-positive is access to anti-retroviral therapy (ART), if they meet the medical eligibility criteria and if ART is available. Without the likelihood of receiving treatment, however, being informed of an hoped-for

[7] This terminology is still widely used and is synonymous with client-initiated testing and counselling in this thesis.

availability of treatment at some unspecified future time cannot transform that burden into a benefit (Macklin 2005:27-28).

By and large, client-initiated testing and counselling is the method of testing currently practiced in South Africa, though these practices are gradually changing.

Provider-initiated testing and counselling (formally routine counselling and testing) has been growing in popularity due to the low levels of uptake of voluntary HIV testing. PITC is initiated by the health care practitioner rather than the patient and is not necessarily accompanied by pre-test counselling. In its original form (UNAIDS/WHO 2004), the intention of RCT was to normalise HIV by including the test in a routine medical exam where consent was already implied. The method included an "opt-out" option where patients could, and had to, explicitly ask not to be tested. In response to the argument that routine HIV testing was a violation of human rights, proponents of RCT believe that "procedures that safeguard a patient's autonomy at the expense of his or her health and well-being undermine the moral and logical basis of human rights themselves" (Heywood 2005:15). UNAIDS and WHO continue to stand by their recommendation that "routine offer of HIV testing should be made to all patients being seen in clinical and community health service settings where HIV is prevalent and antiretroviral treatment is available" (UNAIDS/WHO 2004:2). They have, however, amended their terminology from "routine testing" to "provider-initiated" testing in response to a need to ensure that even this form of testing must be considered voluntary. There is also hope that with a stronger emphasis on the "opt-out" approach, coercion from practitioners will be reduced and patients will be able to assert rights over their own health, as they are with VCT (WHO/UNAIDS 2007). With much local support, Botswana has adopted a routine testing policy[9] and has committed to providing ARVs to all those who need them (Weiser, et al. 2006).

Unlike Botswana, South Africa has adopted the VCT approach (with some exceptions) to HIV testing and as discussed in the motivation above, has low levels of HIV testing. The following section discusses and critiques four factors that have been used to account for these low levels of testing.

2.3.2 Barriers to HIV testing

Research conducted into HIV-related health seeking behaviour has identified a range of factors which may explain why testing levels are low in South Africa. The four significant factors discussed below include: a lack of access to HIV testing services; a lack of knowledge of HIV/AIDS-related

[9] Botswana adopted a method of routine testing before the WHO/UNAIDS (2007) amended their terminology to "PITC."

issues; a lack of treatment for HIV/AIDS; and high levels of stigma. Below, each of these barriers is reviewed and critiqued. These barriers become important in the subsequent discussion about the various methods of testing (VCT and RCT) which attempt to increase rates of testing by addressing these factors. They will also be discussed in relation to the empirical data in Chapters 4 and 5.

Lack of access to testing services

Low rates of testing in South Africa, and in fact in most of the developing world, have been attributed to a limited access to testing services (Hutchinson and Mahlalela 2006; UNAIDS 2004; Weiser, Heisler, et al. 2006). With inadequate material and human resources, many African countries experience weakened health care systems (Asante 2007:644). Throughout sub-Saharan Africa, the availability of VCT is "constrained by shortages of skilled service providers, inadequate material resources, poor infrastructure and inadequate procurement and supply management systems" (Matovu and Makumbi 2007:1316). Increasing access to testing services is believed by some to lead to similar increases in the numbers of adults who voluntarily test for HIV (Matovu and Makumbi 2007; Pronyk, Kim, et al. 2002).

While not all areas have uniform coverage of VCT services, South Africa has a stable and growing health infrastructure. In 2002, there were roughly 450 VCT centres and 800 trained counsellors around the country (Department of Health 2002b; Kalichman and Simbayi 2003:442). In 2005, the Department of Health reported over 3,200 designated VCT sites with more than 450 in the Western Cape alone (Department of Health 2005). In addition, free HIV testing is available at primary health care facilities and hospitals throughout the country. To enhance this even further, the Department of Health has included in the 2007 NSP the need to scale up voluntary counselling and testing coverage by increasing "access to VCT services that recognise diversity of needs" (SANAC 2007:11). The current and growing number of HIV testing sites has been clearly felt, shown by a recent South African population survey which reported that 80% of the population could name a place where HIV testing was offered (Shisana, et al. 2005:86). This is similarly demonstrated by the empirical data in this study where 14 out of 15 participants had been tested for HIV, suggesting that structural constraints (such as financial, geographical, availability of testing services, etc) were not present, or at the very least were not insurmountable, for the participants in the current study. Though clearly a barrier in many areas, a limited access to testing services is not sufficient in explaining low levels of testing.

Lack of knowledge

A common, though increasingly outdated explanation for low rates of testing and continued unsafe sexual practices in South Africa is that there is a lack of awareness about HIV/AIDS related issues among the majority of South Africans. Using cognitive-behavioural theories[10] of human behaviour, HIV knowledge is frequently considered in studies which seek to explain low levels of testing behaviour or poor adherence to prevention and treatment initiatives (Gebrekristos, Lurie, et al. 2005; Kalichman and Simbayi 2003; Kalichman, Simbayi, et al. 2006; Nachega, Dara, et al. 2005; Smith and Stasson 2000).

Evidence of the belief that increased knowledge about HIV/AIDS leads to increased protective or preventative behaviours can be seen in South African governmental and non-governmental awareness campaigns. *Khomanani*, for example, is a government-led initiative headed-up by the South African Department of Health. The campaign, whose name means "Caring Together," is a communication strategy designed to focus on HIV prevention, care, treatment, and health promotion (Cullinan 2003). A statement issued by Meropa Communications, the tender hired by the Department of Health to manage the campaign, explains the intentions of Khomanani:

> The campaign adopted a behavioural change framework that sees individuals and communities progressing along a five-step process from ignorance towards knowledge, approval, intention, practice and advocacy. While some individuals may be further along this process, it begins with ignorance of HIV and AIDS risk and consequences, and then proceeds to knowledge of these. This is followed by an approval of strategies to overcome these risks and prevent these consequences, and next is the intention to apply these strategies. The framework suggests that this will hopefully lead to the practice of these strategies, and finally to advocating for others to do likewise (Department of Health 2003).

Similar to campaigns promoting HIV prevention through increased knowledge about HIV, treatment literacy campaigns have sought to educate HIV positive people about how and why antiretrovirals (ARVs) work in order to increase ARV uptake, adherence, and success. Many campaigns view increased HIV knowledge as the key to practicing protective sex, adhering to treatment, and accessing testing and treatment services[11]. As is evident in the Khomanani campaign, "individual

---

[10] Such theories include the Health Belief Model, Social Cognitive Theory (Bandura 1997; Bandura 1977), the Theory of Reasoned Action and Planned Behavior (Fishbien and Ajzen 1975; Azjen 1988), and Knowledge-Attitudes-Practices, among others.

[11] Other campaigns in South Africa that have focused on changing knowledge and attitudes include *loveLife* and Soul City, as well as the age-appropriate HIV/AIDS education that has been included in South African school-based life orientation programmes. loveLife advocates abstinence, partner reduction, and increased condom use by attempting to "change the pervasive values and attitudes among young people to sex, sexuality, and gender relations" (loveLife 2004:2). Soul City makes part of its widespread television, radio, print media, and government lobbying campaign the reliance on imparting "information and impacting on social norms, attitudes and practice" (Soul City 2008). HIV/AIDS curricula has been included in South African schools since 1998 (Nattrass 2007) and has nationally-defined but province-regulated subject matter

and interpersonal theories (such as the Health Belief Model...) have so far been the ones most influential in the development of HIV prevention interventions" (Mathews 2005:151).

However, despite the importance of awareness about AIDS, there are two primary objections to the view that low levels of knowledge about HIV/AIDS or the benefits of HIV testing are the cause of such low testing rates. Firstly, "whilst there appears to be a logical connection between concepts of health, beliefs about health maintenance, and health-related behaviours, empirical evidence suggests that their importance may in fact have been overestimated, and that the relationship between knowledge and action is a problematic one" (Williams 1995:580). For prevention, for example, it is a harmful misconception that lack of knowledge about the ways HIV is transmitted and the methods for HIV prevention is the cause of unsafe sexual practices. To the contrary, it is well documented that people "knowingly engage in sexual behaviour that could lead to a slow and painful premature death" (Campbell 2003:1). Likewise, the expectation that "knowledgeable and empowered HIV-positive clients" will take responsibility for correctly adhering to life-long antiretroviral treatment is ignorant of the actual experience of living with HIV, which can often be traumatic in the alienating and sometimes hostile environment of HIV/AIDS in South Africa (Robins 2006:313). Similarly with HIV testing, it has already been shown that many people chose not to test despite knowing the benefits of learning one's status early.

Secondly, the notion that South Africans are unaware of HIV-related issues and the importance of HIV testing is unfounded. In 2005, a South African national HIV population survey found proficient knowledge in various areas of HIV, ranging from its transmission to the ways it is treated or prevented. For example, the survey reported that 93.9% of 15-24 year-olds and 95.7% of 25-49 year-olds correctly believed that HIV could be transmitted through unprotected sex. More than 80% reported that there was no cure for AIDS and 84.6% said they would seek ARV treatment in order to "extend life or live longer" (Shisana, et al. 2005:89). The survey stated that while knowledge varies across age groups, "overall, implicit knowledge is high" (Shisana, et al. 2005:86-87), suggesting that low levels of testing are also not due to a lack of knowledge about HIV/AIDS or ARVs. A study about HIV testing in South Africa found no difference in HIV knowledge between those who had and those who had not tested for HIV (Kalichman and Simbayi 2003). In fact, studies have consistently shown that "HIV testing history [is] not associated with AIDS related knowledge" and that "factual based education about HIV transmission is necessary but insufficient in promoting HIV antibody testing"

(Department of Health 2002a). The Western Cape school system uses its position "as the primary transmitter of knowledge, skills and values to the youth of society – to raise HIV-awareness, to disseminate information about HIV and its transmission, and to help change the attitudes of young people to inhibit the spread of the epidemic" (Western Cape Education Department 2002).

(Kalichman and Simbayi 2003:446). Participants in this study demonstrated high knowledge of AIDS and HIV and heavily advocated HIV testing. However, it will be shown that this factual knowledge alone cannot account for their testing behaviour. Lack of knowledge about HIV/AIDS, then, does not form a causal link to the low levels of testing in South Africa. Furthermore, the findings of this study suggest that there is a need to understand more carefully what kind of knowledge exists around HIV, not only in terms of how it is treated or prevented, but also about the perceived consequences of living with HIV and how this affects low levels of testing.

Lack of treatment

Support for HIV testing has historically been compromised by the lack of an effective treatment response once an individual was diagnosed HIV-positive (De Cock, et al. 2002). In the absence of HAART in South Africa, resistance to getting tested or to knowing one's own status has been attributed to fear of being HIV-positive caused by the association between AIDS and death (Shisana, et al. 2005). For example, one study from South Africa explicitly demonstrates that a "fear of death" is the reason for some individuals' refusal to take an HIV test (Day, Miyamura, Grant, et al. 2003:668). Another study shows that a group of youth from Durban, South Africa actually viewed an HIV-positive diagnosis as *equivalent* to the ending of one's life and as a result, many would choose not to test for HIV, donate blood, or use the same clinic twice simply to avoid ever finding out if one was infected (Leclerc-Madlala 1997:368).

In Sontag's *Illness as Metaphor* (1978) she demonstrates that diseases which are not fully understood, and more importantly, are without effective treatment, instil the greatest fear. Her earlier work draws on examples primarily from tuberculosis (TB) and cancer, citing that "not so many decades ago, learning that one had TB was tantamount to hearing a sentence of death – as today, in popular imagination, cancer equals death" (Sontag 1978:7). The language linking a diagnosis to death, rather than death to the chronic illness itself, is repeated in the current discourse around HIV/AIDS. A study done with mineworkers in South Africa found that many believed a lack of a future and the cessation of "everything" follow a positive diagnosis and therefore many refused to take an HIV test (Day, et al. 2003:668). Sontag goes further to suggest that the development of treatments for TB facilitated the reduction of fear associated with the disease (1978:35). In her later work, Sontag suggested that AIDS had replaced cancer as the most feared disease, in part because it was "extremely recalcitrant to treatment" (Sontag 1989:16)[12]. Inline with Sontag's observation that

[12] Indeed, in 1989 when Sontag was writing about HIV/AIDS, effective ARV treatment had not yet been developed. A combination of drugs now known as HAART was finally approved for use in 1995 (Merson 2006) and has been available worldwide since 1996 (Wood 2005:505). HIV/AIDS is no longer considered "extremely recalcitrant to treatment."

tuberculosis treatments reduced fears associated with the disease, it has been speculated that improved and widely available antiretroviral therapy could similarly reduce fear of AIDS and potentially encourage HIV testing.

Thus, the scale-up of ARV treatment has been viewed as a "vital step towards encouraging testing in sub-Saharan Africa" (Asante 2007:644). Lessons from other countries that are also battling with AIDS epidemics demonstrate that increased access to ARVs encourages testing evidenced by substantial increases in VCT. In Brazil, for instance, when the national government announced in 1996 that it would provide antiretrovirals for free through the public health care system, people "who had not yet been diagnosed decided to be tested on the basis of information about the effectiveness of the drugs and their availability free of charge" (Galvão 2002:1863). In Botswana, a survey about the benefits of routine HIV testing showed that 67% of those who had not been previously tested for HIV would do so "knowing that they could get treatment for HIV/AIDS" (Weiser, et al. 2006:1018). Knowledge that ARV treatment was available was also one of the most common motivational factors for testing cited by those who had already participated in VCT. Similarly, "the advent of therapy in industrialised countries has greatly increased motivation for people to be tested" (De Cock, et al. 2002:68).

Since the South African government's commitment to providing HAART nationally in 2003 and the eventual rollout (after severe delays) in 2005 (Butler 2005; Heywood 2004; Leclerc-Madlala 2005; Nattrass 2007), the increasingly viable option of providing a good response to an HIV positive status has the potential to increase the uptake of HIV testing. This is because it is widely speculated that the knowledge that ARV treatment is available in the event of a positive test result will function to allay the fears of those who would normally choose not to test for fear that they would be positive (Nattrass 2003:10). Researchers within South Africa have found correlations between knowing someone on ARVs and likelihood of being tested, suggesting that "the availability of ART may lead to an increase in the uptake of counselling and testing services" (Mfundisi, et al. 2005:485). Similarly, this study concurs with the above assertion but argues that treatment alone is not sufficient in encouraging the uptake of HIV testing.

High HIV-related stigma

According to UNAIDS and WHO, while access to HIV testing services is limited in lower- and middle-income countries, "the reality is that stigma and discrimination continue to stop people from having an HIV test" (UNAIDS/WHO 2004:1). This is because "stigmatising beliefs about AIDS and their

associated fears of discrimination can influence decisions to seek HIV testing and HIV treatment services" (Kalichman and Simbayi 2003:442).

Brought into popular academic literature by Goffman (1963), stigma has been widely used to explain the treatment and experiences of HIV positive persons. Originally interpreted as a literal "mark" on the body which signified social or moral ignominy, stigma is now considered to create a "spoiled identity" for people who bear an undesirable characteristic, whether visible or not. Though written before the years of the AIDS epidemic, Goffman's three types of stigma, "abominations of the body," "blemishes of individual character," and "tribal stigma of race, nation and religion" (1963:4), are useful when understanding the impacts and root causes of HIV/AIDS- related stigma.

Throughout history, stigmatisation has negatively impacted the health and well-being of individuals affected by stigmatised conditions. Infectious diseases (and in this case sexually transmitted) are particularly stigmatised, and often result in

> exclusion and disempowerment [that] can impede access to prevention and care services, in particular access to treatment that can cure or suppress infection. [Stigmatisation] can also increase vulnerability to being exposed to infection or becoming infected because precautions cannot be implemented (Gilmore and Somerville 1994:1343).

In the context of the AIDS epidemic, "stigma is perhaps the greatest dread of those who live with AIDS and HIV – greater to many even than the fear of disfiguring, agonising and protracted death" (Cameron 2005:53). Stigma is considered to compromise the effectiveness of HIV awareness and prevention initiatives and discourage individuals from testing for HIV, accessing treatment and care services, and disclosing their status to friends or family members (Almeleh 2006; Daftary, Padayatchi, and Padilla. 2007; Hutchinson, Mahlalela, and Yukich 2007; Kalichman and Simbayi 2003; Kalichman, et al. 2006; Parker and Aggleton 2003; Skhosana, Struthers, Gray, and McIntyre 2006; Simbayi, Kalichman, et al. 2007). The UNAIDS Reference Group explains that "reducing HIV/AIDS-related stigma and discrimination at all levels, notably within health care settings" (2005:43) is a key factor for increasing the demand for voluntary HIV testing.

In contrast with this belief, the HSRC study shows that less than 1% of South Africans report that they do not test because they are "concerned about stigma" and an increasing number of people are voluntarily seeking out testing services because they "want to know" their status (Shisana, et al. 2005:83-85). However, it is unlikely that the effects of stigma are as insignificant as this study suggests, and the low response rate regarding stigma's effect on testing may be due to problems with self-reporting of this information. Countless studies and reports demonstrate the powerful

impact of HIV stigma (Almeleh 2006; Daftary, Padayatchi, and Padilla. 2007; Hutchinson, Mahlalela, and Yukich 2007; Kalichman and Simbayi 2003; Kalichman, et al. 2006; Parker and Aggleton 2003; Skhosana, Struthers, Gray, and McIntyre 2006; Simbayi, Kalichman, et al. 2007). In any case, the debilitating impacts of stigma cannot, on their own, account for the low levels of HIV testing in South Africa.

Each of these barriers to HIV testing discussed above must be considered when understanding the reasons for low levels of testing in South Africa. However, no one factor can be looked at in isolation and all of these factors must be looked at in a broader biopsychosocial experience of living with HIV. Empirical Chapters 4 and 5 address these barriers to testing in the context of the perceived experience of living with HIV and role that testing plays in either mitigating or exposing an individual to the threats of being positive.

2.3.3 Increasing Uptake of HIV Testing: client-initiated or provider-initiated testing?

At the core of the debate between HIV testing as a human right or a public health issue, the decision to implement either client-initiated testing and counselling or provider-initiated testing and counselling is also central when discussing strategies to increase levels of HIV testing. Support for PITC, in particular, forms a response to the barriers discussed in the above section.

Proponents of PITC argue that in order to eliminate the testing barriers of access, knowledge, treatment, and stigma, provider-initiated testing must be implemented. Those who hold this view state that "A commitment to the routine offer of testing has also become necessary because in most developing countries easy access to counseling services, an HIV test, and information about AIDS in health facilities has been as scarce as antiretroviral drugs" (Heywood 2005:14). Furthermore, arguments for PITC often criticise traditional VCT methods, stating that the client-initiated nature of testing is the cause for such low testing rates.

> Relying on the traditional model of voluntary counseling and testing (VCT) will not result in adequate numbers of people tested to meet treatment and prevention goals because it is client- rather than provider-initiated and is onerous in time and counseling requirements. The ambitious goals defined by the international community would have been doomed to failure without a change in HIV testing policies and practices so that millions of HIV-infected persons can be rapidly identified and assessed (De Cock 2005:33).

When addressing stigma as a barrier to testing, many believe that the routine offer of HIV testing will help to reverse the stigma and discrimination that has come to be associated with the virus because of the silence and fear thought to be caused by voluntary testing (Cameron 2005; De Cock, et al. 2002; Heywood 2005). Because of the increase in absolute numbers of those who will be

tested due to PITC, many hope that "greater use of testing will, in time, lead to HIV/AIDS' being seen as a chronic, treatable condition like many others, eventually diminishing the stigma associated with HIV and stimulating demands for HIV testing more broadly" (Tarantola 2005:38). With either method of testing, the goal is to increase the number of people who are aware of their status so that treatment and prevention interventions can be implemented.

2.4 Beyond the HIV test

2.4.1 Illness and Disease

Differentiating between disease and illness is useful in understanding AIDS and HIV testing behaviour. Many people have theorised about individual and social understandings of disease and illness and how these impact not only how humans behave in relation to their health, but also how they interpret different states of health and illness (Helman 1981; Helman 2000; Kleinman 1980).

In a breakdown between medical models of the virus and social experiences of AIDS, Kleinman differentiates between disease and illness by saying that the former is a biomedical practitioner's understanding of pain or bodily malfunction while the latter is the patient's "psychosocial experience and meaning of [the] perceived disease" (Kleinman 1980:72). The contrasting ways that patients and practitioners view disruption in the body highlight the difficulty in treating or managing disease and illness. Scepticism with a medical practitioner's diagnosis may arise and patients may be "dissatisfied" with a physician when their expectations of health and recovery are not met.

> when physicians consider symptoms, they focus on the pathophysiologic processes of the disease that produces them. But when patients have a symptom, they are often most concerned with its effect on health-related quality of life and the objective experience of illness (Hahn 2001:903).

This happens because a medical practitioner is trained to look for physical symptoms that signal disease while disregarding social, financial, or emotional impacts of illness. The patient, on the other hand, may interpret physical symptoms as minor or secondary to the practical implications they have on life processes. Thus, even if medical treatment for the disease is prescribed, the pain or distress felt by the patient may not dissipate (Kleinman 1988:6).

2.4.2 Biopsychosocial Model

In recognition of the failures of biomedicine to fully diagnose and treat diseases, Engel (1977) proposed a biopsychosocial model to incorporate patients' experiences into medical understandings of ill-health. Unlike the traditional biomedical model, which Engel argues is inadequate in

understanding the human condition, a biopsychosocial model uses social and psychological, factors as well as biological, to describe when patients feel sick, how they understand and describe their symptoms, when they seek medical treatment, what kind of medical treatment they require, and whether or not the medical treatment is effective (1977:131-132).

> The dominant model of disease today is biomedical, with molecular biology its basic scientific discipline. It assumes disease to be fully accounted for by deviations from the norm of measurable biological (somatic) variables. It leaves no room within its framework for the social, psychological, and behavioral dimensions of illness (Engel 1977:130).

Similar to discourse on the difference between disease and illness, Engel's biopsychosocial model also speaks to the relationship between the patient and the physician, or rather the breakdown in communication and understanding between the two; the physician responds to disease-oriented symptoms while the patient is informed by and concerned with the illness experience.

The biopsychosocial model is most commonly used to explain the *determinants* of disease or *expressions* of illness (Engel does not distinguish between disease and illness in quite the same way as does Kleinman) rather than the social and psychological *experiences* of a particular biological condition. Therefore, a focus on the biopsychosocial model is useful for understanding HIV testing merely because it illuminates the multiple and varied experiences of living with HIV and how an HIV test – the gateway to discovery of status – may contribute to or facilitate undesired illness.

2.5 Conclusion

HIV/AIDS is a heavily medicalised condition (Tarantola 2005) and the separation between AIDS disease and AIDS illness has created problems for prevention, diagnosis, and treatment in South Africa. Biological-based AIDS education, behavioural change prevention messages such as abstinence and condom usage, regular testing and early detection, and provision of HAART are all strategies that have focused on AIDS disease. They prioritise containing the HI-virus, diagnosing opportunistic infections and positive HIV-status, and managing disease with medical drugs. However,

> in the practitioner's act of recasting illness as disease, something essential to the experience of chronic illness is lost; it is not legitimated as a subject for clinical concern, nor does it receive an intervention. Treatments assessed solely through the rhetoric of improvement in the disease process may confound the patient's (and family's) assessments of care in the rhetoric of illness problems (Kleinman 1988:6).

This thesis will demonstrate that "low use of HIV testing is also largely understood to result from individuals' fears of the health and social consequences of a positive diagnosis. Incidents of social rejection, loss of employment, family disruption, and violence continue to fuel these fears, as they have since the beginning of the epidemic" (Tarantola 2005:40). It will argue that testing services must consider individual experiences of living with HIV and be structured according to the needs of those attending VCT clinics. Furthermore and in conclusion,

> Until treatment can be offered consistently to those diagnosed as HIV-infected, and in the absence of effective protection against discrimination, imposing an HIV test by law – or worse, without legal backing – amounts to unsound public health practice. *If mechanisms and means are in place to provide quality services and an environment protective of the rights of those who seek testing, there is every reason to expect that the voluntary demand for testing and care will grow steeply* (Tarantola 2005:40; *author's italics*).

Thus, "addressing the *implications of* a *positive test result,* including non-discrimination and access to sustainable treatment and care for people who test positive" is a crucial factor for increasing the demand for voluntary HIV testing (UNAIDS Reference Group 2005:43).

Chapter 3 – Methodology

3.1 Introduction

This study was conducted during 2007 with 15 young adults from two African townships surrounding Cape Town in the Western Cape province of South Africa. Townships are defined as urban informal areas created during apartheid that functioned to racially segregate the South African population. "African" is a term that was used by the apartheid government to classify people based on skin colour. Townships have historically been constructed of a single "race" category of "non-whites" (African, Coloured, or Indian). As a result of their institutionalised economic and geographical separation, townships continue to be largely single-race and characterised by poverty and unemployment.

The two primary locations for both participant recruitment and qualitative interviewing were the townships of Nyanga and Khayelitsha. Interviews took place at clinics, universities, and a community centre, depending on which location was most convenient for the research participant. Table 1 shows the demographic and socio-economic information for the areas of Nyanga and Khayelitsha.

TABLE 1: Demographics and Socio-economic Information

	Nyanga	*Khayelitsha*
Percentage of population classified as African	99.54	99.42
Percentage not graduating from high school	77.52	75.26
Percentage unemployment in the economically active population	56.00	50.80
Percentage living in informal dwelling	38.76	57.05
Percentage earning <R1 600 per month	79.53	77.83
Percentage earning <R19 200 per annum	72.33	71.92

(Source: City of Cape Town 2003-2008 and Statistics South Africa.)

Information from Table 1 pertaining to population group ("African") and locality type ("informal dwelling") are referred to below when providing a justification for the target population. The employment status and years of schooling of the participants in this study (presented below in Table 2) show that the study sample is not representative of the population from Nyanga and Khayelitsha, with the participants showing a slightly lower unemployment rate (46%) and a much higher rate of

graduation from high school (66% in the sample graduated high school compared to a population average of roughly 25%)[13].

3.2 Study design

The method of data collection for this study was in-depth, semi-structured qualitative interviews. Participants were each interviewed once and an interview guide was used (see: Appendix 1). Pilot interviews were conducted to establish the question selection and sequencing. However, the order of questioning was flexible and primarily driven by the participants. This allowed for a wider range of responses while still uniformly obtaining certain pieces of information. This process struck a compromise between unstructured interviews and structured interviews, the former which calls for a "minimum of control of people's responses" but relies on multiple interviews, and the later which is reserved for when the researcher "won't get more than one chance to interview someone" (Bernard 2006:211-212). The degree of flexibility is modelled after work by Bourdieu (1986; 1990), who criticised most social science research for its unoriginality. An interpretation of Bourdieu's criticism highlights the value of a flexible interviewing style.

> Social scientists tend to be too easily satisfied by evidence obtained through commonsense experience or by familiarity with certain intellectual traditions. One of the most important consequences of this influence is that the structure of a field proposes (to those who are in the field) a problem-structure (or possible questions) which orients the activities and research that occur within the field, and serves to limit the range of possible legitimate questions (Mahar, Harker, and Wilkes 1990:2).

This same support for more fluid types of data collection is echoed in Glaser and Strauss' Grounded Theory, which calls for highly unstructured interviews and observations as well as loose research questions and minimal expectations (Glaser and Strauss 1967). With cognisance of the time restrictions on the research conducted here, a variation of modified grounded theory was used, and one that respects Bourdieu's value of limited control over research outcomes so as to foster the generation of new ideas. The analysis section below describes how a modified grounded theory approach to qualitative data analysis works.

All interviews were conducted by myself, were completed in English, and lasted roughly an hour. They were recorded and subsequently transcribed verbatim to prepare for data analysis. I reviewed

---

[13] It is key to note that the population in this study was between the ages of 19 and 25 (with one participant at 31), while the demographics from Table 1 reflect the whole population of either Nyanga or Khayelitsha. Years of schooling will be higher in younger populations who attended school in post-apartheid years, while employment in younger populations may also be higher due to more years of schooling.

all interview recordings following each interview to allow for reflection and improvement in interview style. Specific attention was paid to the clarity and wording of questions, the silences during and between questions, and the interruption and misinterpretation patterns during the interviews.

3.2.1 Measurement

The semi-structured qualitative interview format was able to allow for the collection of demographic and historical information about each participant. The remainder of the content in the interviews focused on how participants engaged with AIDS and HIV in their lives. Feelings towards and circumstances around HIV testing were specifically explored, though many of the understandings of HIV testing were garnered though discussions of other topics. Six specific areas were discussed: 1) participant's first encounter with HIV/AIDS; 2) factors leading to the development of their current feelings towards HIV/AIDS; 3) sources where information about HIV/AIDS was obtained; 4) participant's personal testing experiences; 5) participant's ideas about what happens after an HIV test; 6) and participant's evaluation of how to encourage HIV testing. Although the consistency of these topics in each interview would appear to suggest a high level of structure in the questioning process, many of these patterns were organic and were in fact directed by the participants.

3.3 Population and Sample

The youngest participants in the sample were 19 years old and only one was over the age of 25. The sample was made up of 6 men and 9 women. Six of the participants lived in Nyanga, 3 in Khayelitsha, 2 in New Crossroads, and 1 each in Mitchell's Plain, Bellville, Lower Crossroads, and Guguletu. Seven reported that they were born or raised outside of Cape Town (either the Eastern Cape or Kimberly) but all currently resided in the Cape Town area. The areas of Nyanga, Lower Crossroads, and New Crossroads are neighbouring townships and therefore utilise many of the same services including community resources, health care facilities, and transportation. Khayelitsha is a considerable distance away from Nyanga. The maps in Appendix 2 illustrate the distance between these townships, as well as the distance from Nyanga and Khayelitsha to the Eastern Cape where many people still travelled to visit family. The part of the Eastern Cape where participants' families still lived is largely rural and has different access to education, resources, and health care facilities than the urban townships in which they now lived.

Table 2 below shows the age, gender, and location of residence for each of the participants. The table also includes information about home language, years of schooling, employment status, testing

behaviour, and reported HIV status. Not all participants reported how many times they had tested for HIV so the information is only included in the table where it was available. The HIV status of the participants was not known when they were selected to participate in the research but it was revealed by the participants wilfully during the interviews. Two participants were living with HIV and one was currently taking antiretrovirals.

Table 2: Participant Biographical Information and HIV Testing Behaviour

Name	*Gender*	*Age*	*First Language*	*Residential area*	*Hometown/Grew Up*	*Employment status at time of interview*	*Schooling*	*Testing Behaviour*	*Reported HIV status*
Andiswa	Female	25	Xhosa	Delft/ Belville	Eastern Cape	Employed	Did not finish high school; failed grade 12	Yes	Negative
Bulelani	Male	25	Xhosa	Guguletu	Umtata, Eastern Cape	Employed	Matric 2003; some tertiary	Yes	Negative
Dumisani	Male	20	Xhosa	Khayelitsha	Cape Town, Khayelitsha	Employed	Matric; Cape Technikon	Yes, 2 times	Negative
Kwanie	Female	31	Xhosa	Khayelitsha	Eastern Cape	Employed	Matric; adult education classes	Yes, 1 time	Positive; on ARVs
Lindiwe	Female	25	Xhosa	Khayelitsha	Eastern Cape	Employed	Langa Finishing School	Yes, 2 times	Negative
Nobantu	Male	20	Xhosa	Lower Crossroads	Pritchard West, Eastern Cape	Unemployed	Matric 2004	Yes, 1 time	Negative
Noneka	Female	24	Xhosa/ Afrikaans	Mitchell's Plain	Cape Town	Unemployed	Did not finish high school; left in grade 9	Yes, 2 times	Positive, not on ARVs
Philani	Female	19	Xhosa	New Crossroads	Cape Town	Unemployed	Matric 2006	No	Hasn't tested
Sethembile	Female	19	Xhosa	New Crossroads	Cape Town	Unemployed	Did not finish high school; left in grade 10	Yes, 1 time	Negative
Sipho	Male	23	Xhosa/ Afrikaans	Nyanga	Kimberly, Northern Cape	Unemployed	Matric 2005	Yes, 1 time	Negative
Sizwe	Male	20	Sotho	Nyanga	Cape Town, Nyanga	Employed	Did not finish high school	Yes, 4 times	Negative
Vusi	Male	21	Xhosa	Nyanga	Port Elizabeth, Eastern Cape	Employed	Matric 2004; classes at Damelin	Yes, 3 times	Negative
Xola	Female	20	Xhosa	Nyanga East	Cape Town	Employed	Matric 2004	Yes, 1 time	Negative
Zanele	Female	23	Xhosa	Nyanga/ Zwelitsha	Cape Town	Unemployed	Matric 2005	Yes, 1 time	Negative
Zolani	Female	21	Xhosa	Nyanga/ Zwelitsha	Cape Town	Unemployed	Matric 2004	Yes, 3 or 4 times	Negative

3.3.1 Reason for target population

One reason for interviewing young African youth from townships around Cape Town returns to the discussion of statistics. Although infection rates are high in South Africa, HIV prevalence is not evenly distributed across the population. From a gendered perspective, for example, women have a prevalence rate of 13.3% while men have a rate of only 8.2% (Shisana, et al. 2005:34). Similarly, a look at the distribution of HIV across age groups shows that young, working age adults are carrying a higher burden than younger or older generations.

The highest infection rates in South Africa are found among people between the ages of 25 and 34 (Shisana, et al. 2005:34). With only three participants being 25 and one at 31, the majority of those interviewed in this study are about to enter this high prevalence population. Furthermore, incidence rates for the study population are higher than any other age group. Indeed, "more than half of all new infections globally are in the young people aged 15-24" (Harrison 2005:264). For a study on HIV testing and either management of a positive status or prevention of future infection, exploring the high incidence, soon-to-be high prevalence population is of useful significance. A further look at the prevalence rates among population groups shows that Africans have the highest rate of infection at 13.3% compared to the next highest rate of 1.9% among the Coloured population (Shisana, et al. 2005:80). Lastly, all participants lived in townships, classified as "urban informal" areas by the HSRC National HIV Survey. This locality type has an infection rate of 17.6%, significantly higher than any other locality type (Shisana, et al. 2005:80). When age and population group as well as age and locality type are looked at together, prevalence rates for the population the participants belong to are incredibly high. For Africans aged 15-24-years, 1 in 6 are infected with HIV. For 15-24-year-olds living in urban informal areas, close to 1 in 5 are infected (Shisana, et al. 2005:82).

Another reason for choosing participants that belong to a group with particularly high HIV statistics is that they are labelled by society as being "high risk." Although though the notion of high risk "populations" has been abandoned for concept of high risk "behaviours," blame and "othering" discourses directed at certain populations still accompany prevention, testing, and treatment interventions. The experience of young black South Africans from urban townships, regardless of the actual prevalence rates or sexual practices, allows for a particular type of investigation into the outcomes of bearing the social burden of disease. As is evident through the interviews, many participants were aware of the stigma linking HIV/AIDS to being either "poor" or "African."

3.3.2 Recruitment and Access

Despite the variety of locations of residence, all participants were recruited in either Nyanga or Khayelitsha through convenience sampling. Participants were identified to participate in a number of ways but one crucial denominator was that I held a strong relationship with each of them. Ten of the participants were recruited from a workshop that was being run by the University of Cape Town student volunteer organisation, SHAWCO. The workshop is held at the Nyanga SHAWCO Centre in Zwelitsha (a section of Nyanga) and runs for 10 weeks, twice a week. It addresses topics such as HIV/AIDS, crime, violence, drugs and alcohol, and other health-related issues. The workshop is targeted at young men and women in Nyanga and those who participate have been self-selected. I created and ran the workshop at the Nyanga SHAWCO Centre in 2006 and 2007 and subsequently recruited the participants to take part in this study.

Three participants were involved with another research project being conducted at a Khayelitsha clinic through the University of Cape Town. These participants were interviewers for a sexual behaviour and HIV transmission study that I was heading up as project manager. The two remaining participants were both recruited for pilot interviews and we had a friendly relationship through work or play. The information gained in the pilot interviews was valuable and will be included in the findings.

3.4 Analysis

This thesis makes use of modified grounded theory to conduct a data analysis on qualitative interviews. Grounded theory has as its primary focus the generation of theory. By generating new theory using the data collected in this study, "grounded theory can help forestall the opportunistic use of theories that have dubious fit and working capacity" (Glaser and Strauss 1967:4). In this way, modified grounded theory analysis helps to eliminate the blinders put on by a researcher who uses only certain examples to "prove" ideas that were not created by those examples.

After interviews were transcribed verbatim, themes were extracted from the interviews and recorded in a spreadsheet. This process is known as "coding" the interviews. Unlike thematic analysis, every theme that could be identified from the interviews was included. This is because in grounded theory, "the number of cases [reporting a particular theme] is not so crucial. A single case can indicate a general conceptual category or property" (Glaser and Strauss 1967:30). Ideally, the goal of grounded theory is to get the widest range of data possible on a particular conceptual category and research is not considered complete until "saturation" is reached. Due to time

restrictions, it cannot be confirmed that saturation of information was reached in this study but grounded theory analysis has allowed for the discovery of basic categories and their properties which will give way for future research (Glaser and Strauss 1967:62).

It has also allowed for the generation of a theory to explain the data. Once all the themes were recorded, conceptual categories were identified to prepare for the generation of theory. Chapters 4 and 5 present the conceptual categories that were identified after the coding of data and illustrate the new theory that was generated through organising these categories. This method of data analysis allows for the generation of theory because "one generates conceptual categories or their properties from evidence; then the evidence from which the category emerged is used to illustrate the concept" (Glaser and Strauss 1967:23).

3.5 Ethical Considerations

As with any work with human subjects, there were a number of ethical issues to consider. The added component of working in the field of HIV/AIDS required extra care in maintaining ethical procedures. It was essential that the research was carried out with as much awareness and respect for the rights and needs of the participants in the study.

Informed consent was received from all research participants before the interviews (see: Appendix 3). Each participant was informed of the intentions of the study, both as an investigation of HIV/AIDS testing practices and as a study to be used in fulfilment of a Master's dissertation. Participants were informed that their participation was voluntary, that they could leave the study at any time, and they were able to skip or refuse any questions that they did not want to answer. They were also guaranteed that their anonymity would be maintained at all times. All participants agreed to have their interviews recorded and understood that they could request that the recorder be switched off at any time.

Due to the sensitive nature of the material covered in the interviews, anonymity is maintained at all times through this thesis. No identifying information about the participants is used other than to broadly discuss demographic information (age, gender, location). Interviews are quoted in the text and thus information is not strictly confidential, but pseudonyms are used to assure anonymity of the participants.

Because the power dynamics of an interviewer-participant relationship may cause participants to be uncomfortable or hesitant with refusing to answer questions, it was my responsibility as the researcher to be aware of this and not intimidate or interrogate the participants. Furthermore, recognizing that I had an existing relationship with all research participants, I had to be aware of the impact this would have on data collection in the interview process. In this study, my closeness with the research participants facilitated quality and in-depth discussion and allowed for high comfort levels and greater exploration of sensitive and taboo subjects. This can be reflected in fact that the HIV-status of the participants was raised, unprompted, by each participant during the course of their interviews. It was made clear to participants beforehand that they only needed to respond to questions with which they felt comfortable and that they would not be asked to discuss their own HIV status. Nonetheless, at varying points in each interview, participants openly and willingly discussed their own HIV status.

Information gained in the interviews has been reproduced accurately and in context. When quoting or referring to interviews, it is possible to distort meanings or insert intentions, especially when trying to form an argument. It is imperative that the thoughts and words of the participant are represented as they were intended by the participant as much as possible. It is likely, however, that the filter of the researcher impacts upon the portrayal of information so awareness of this is crucial. Likewise, the analysis of the information generated in discussions, as well as the information gained from other sources, must be presented accurately and with clearly stated assumptions and intentions.

Each participant was informed that he or she is welcome to read the final product. The data generated by this research has the potential of informing policy that will subsequently impact those who have participated. To achieve the full potential of this work, it is necessary that participants offer feedback at each stage in the process.

3.6 Reliability and Validity

This study made use of convenience sampling and therefore is not representative of the population of South Africa. Participants had a higher level of education and employment than was average for their areas where they lived or the country as a whole. Most participants were also recruited from an AIDS education workshop and therefore may have a greater interest or awareness about topics relating to HIV/AIDS than the general population. What is important about this population, however, is that 14 of the 15 participants (93%) had been tested for HIV compared to a national

average of roughly 30%. This unique population allows for an in-depth analysis of the factors that may encourage individuals to test for HIV.

It is impossible to identify or evaluate these contexts or the practices that happen within them in completely objective terms. It is thus important to stress the reflexive nature of this research as "there is no point...from which one can gain a neutral, disinterested perspective" (Postone, LiPuma, and Calhoun 1993:6). My position as a researcher is of crucial importance in evaluating not only what information was able to be obtained during interviews but also how this information was analysed and interpreted. This thesis takes into account the limitations presented above and does not seek to generalise the findings from the empirical chapters. This thesis does, however, note the value of these findings given the unique nature of the sampling group and will give recommendations for future research into the determinants of low levels of testing in countries like South Africa.

Chapter 4 – The threats of being HIV positive

4.1 Introduction

This chapter describes the findings of this exploratory study that set out to uncover the determinants of HIV testing behaviour among a group of young adults living in Khayelitsha and Nyanga. Qualitative in-depth interviews collected information about the 15 participants' own personal experiences of HIV testing, their observations of testing behaviour in the areas where they lived, and their understandings and relationship to HIV/AIDS and HIV testing over time. Through these interviews, it became clear that their perceptions of the outcomes and consequences of living with HIV were inextricably linked to their choices around getting tested.

Participants clearly identified three different perceived outcomes that resulted from being HIV positive. Firstly, they spoke of the disease-oriented symptoms, the visual and functional changes in the body, and the eventual death that was brought on by AIDS. Secondly, they discussed the harmful social responses of family members, friends, neighbours, and other members of their community to being HIV positive. Thirdly, they described the mental break-down, isolation, and depression felt by people who learned they were HIV positive.

As the three outcomes of being HIV positive listed above are seen as undesirable, this thesis will consider them to be "threats" posed on an HIV positive individual. Drawn from the list above, the three threats experienced by an HIV positive person can be conceptualised in the following way:

1. physical threats (physical impact to your body and your functioning organs and the consequences this causes for your working life);

2. social threats (social impact of other people knowing you are HIV positive and therefore treating you differently (negatively) because of this); and

3. psychological threats (psychological impact caused by knowing you are positive and the (harmful) meanings/consequences/realities you believe come with this new identity).

Given each of these outcomes, participants explained how an HIV test served to either mitigate or expose a person to the consequences of living with HIV. Participants believed that physical threats were mitigated by an HIV test because the test served as an entry point for the uptake of HAART and the adoption of healthy living practices that would otherwise be neglected. Thus, perceived physical

threats are to seen to encourage HIV testing. On the other hand, participants also believed that an HIV test exposed an individual to the social and psychological threats that were born out of living with HIV because both public disclosure and private awareness of status resulted from an HIV test. Thus, perceived social and psychological threats can be seen to discourage HIV testing.

Two further points regarding threats and their impact on testing must be addressed. Firstly, the majority of participants in this study (13 out of 15) were HIV negative so it is important to stress that their testing decisions were based on their *perception* of the outcomes of living with HIV and not the actual experience of living with HIV. However, it *is* the perception of each of these threats and the impact that an HIV test has in either mitigating or instigating these threats, that is most integral to understanding HIV testing behaviour.

Secondly, it is necessary to make a distinction between the actual act of testing and the internal or mental desire to test. In countries where HIV testing is voluntary, such as in South Africa, the act of testing requires that an individual wants to test for HIV *and* that HIV testing services are available and accessible. An internal or mental desire to test requires only that an individual is disposed towards testing, even if services are not readily available. This thesis focuses on the latter, which will be termed the "individual bias towards testing." It is important to make this distinction because the three threats which are used to explain HIV testing speak to individual processes which bring an individual to a decision to test. It is only at the intersection of the *opportunity* to test and a bias towards testing that will result in successful HIV testing behaviour[14]. A separate and parallel discussion on the ways to create opportunities to test will necessarily complement this research.

This chapter is divided into three sections, each of which describes one of the threats listed above. Each section first presents the participants' perceptions of the threat and then moves on to explain how this threat either encourages or discourages HIV testing. Perceived physical threats are seen to encourage testing while perceived social and psychological threats discourage testing.

4.2 Physical threat

I think for me, being able to know your status early on, it's more of an advantage than knowing later on that you are HIV positive (Sipho, 23-year-old male).

[14] One can think of the consequences of a population of people disposed towards testing but with no testing services, just as one can imagine HIV testing clinics on every corner that are never utilised.

The first threat that was expressed widely by participants was the physical damage caused by being HIV positive. Participants were well versed in the difference between HIV and AIDS and could accurately describe, either from having learned about it or from personal experience, the symptoms and outcomes that came from living with HIV. However, participants were also acutely aware of the opportunities for survival and strongly advocated ARVs. Accordingly, they stressed the importance of testing as this was the gateway to accessing life-saving treatment and adoption of healthy living practices. In order to show the link between physical threats posed by HIV and the likelihood of testing, participants' responses in the interviews will outline their perceptions of the physical threats and the positive impact of testing in mitigating this threat.

4.2.1 Perceptions of the physical threat

While the negative physical impact of being HIV positive takes many forms, two dominant themes surfaced in the interviews: the threat of AIDS and death and the threat of opportunistic infections.

AIDS and Death

The most frequently stated example that being infected with HIV presents a physical threat was that HIV led to death. The link between AIDS and death was sometimes expressed in clinical terms, seen by a few participants to be an eventual outcome of being HIV positive. When one participant was asked to explain HIV she replied,

> *I think, they say there are stages. You've got stage 1, stage 2, there's stage 3, and then if you in stage 4 then you're in AIDS and then you die. They will say like that (Sethembile, 19-year-old female).*

In other instances, participants expressed the physical damage of HIV in more personal terms, rather than simply as a clinical prognosis.

> *A lot of people are dying because of HIV (Andiswa, 25-year-old female).*

> *I think HIV is a disease that kills people (Lindiwe, 25-year-old female).*

Another participant explained the impact of HIV by explaining who is most affected by the virus.

> *HIV is destroying what we have, you see. The youth is dying because of it. And what I can see, most of the people who are infected is the youth (Nobantu, 20-year-old male).*

A few participants also used language that personified HIV, posing the virus as a "killer."

HIV, what can I tell about HIV? HIV, what can I say, is a serial killer (Sethembile, 19 year-old female).

All 15 participants discussed the relationship between HIV infection and death.

Opportunistic Infections

In addition to linking HIV to death, many participants communicated the symptoms of living with HIV in the advanced stages of infection. They had learned about these symptoms both from educational sources, such as schools and media campaigns, as well as from personal experience with themselves or people they knew. One participant described the experience of learning for the first time that her aunt was infected with HIV.

I remember when we left her; we were in South western in Windhoek. She was so fat but when she came here she was so thin. And then I started to say 'What is this now?' They say 'HIV positive.' She's almost looking like a small baby in the bed. And she was sweating and got lots of spots on the body. And she's even, because she was a white person. Now she starting to turn black colour and started being couldn't take care of herself. She was like a small baby (Noneka, 23-year-old female).

Another participant talked about a friend who was infected with HIV.

I was in PE five years ago and there was a guy, we were the church mates so we used to stay together and he was affected by this disease. You know when you it's hot? Let's say 35 degrees censious (sic) and it's hot and that guy, he was feel cold and wearing a jacket, you understand? So I was afraid too, about that because I know I used to saw somebody with HIV/AIDS and it was difficult for him even to eat because that thing, his throat was sore. So at that time everybody, everybody if you got HIV/AIDS, we know the symptoms, your hair look lighter and you become thinner (Vusi, 21-year-old male).

Like this participant expressed, many people showed that learning of the symptoms of HIV made them afraid of the virus.

Andiswa: I don't want to lie. I'm scared of HIV.

Hannah: What are you scared of?

Andiswa: Uh! When you saw people who are positive, some of them, like those they are serious, maybe they are ill. Some of them their feet, they can't even walk because their feet are painful. So I don't picture myself...And every time, you know every time that one day you are going to die because there is something...you've got virus in your blood (Andiswa, 25-year-old female).

Many participants explained that learning of the symptoms of advanced HIV infection caused them to begin to take HIV "seriously." One participant described his experience of learning about HIV and opportunistic infections at a community project that discussed health issues.

> *Sizwe: We were talking about these projects, ah talking about these issues, like, HIV, you see, and that's where I saw, no man, this is something that (pause) is living and it is something that is huge.*
>
> *Hannah: So what was is that made you think that?*
>
> *Sizwe: Because when they showed us, I think it was some posters. Ja, some posters of people who living with HIV. And those posters of our people from upper Africa countries. And few are South African countries, people. And when I saw that, and I decide. Hannah can I tell you something?*
>
> *Hannah: Yes.*
>
> *Sizwe: What made me realise that HIV was something bad it was when I saw this picture of a young girl. In this upper Africa country. I can't remember the name of the country. But I remember the picture. And this girl was in between 16 and 14, you see? She was as small as a baby. A newly born baby, you see. She was, they were showing a picture before and then they were showing a picture after, when she had this virus. And she was like small in the bed and her mouth it was drrry. And her eyes were inside, eh, ooh. And her skin was like (motions). And I told my self, no! This is a bad virus (Sizwe, 20-year-old male).*

The information gained through education campaigns, as well as the experience of knowing people who had died or were sick due to AIDS-related opportunistic infections, led all 15 participants to consider the physical threat presented by being infected with HIV.

4.2.2 HIV testing to mitigate physical threat

Participants explained how testing and knowing one's status could help to mitigate the physical damage of being positive. Firstly, they repeatedly stressed that although AIDS could lead to death, dying was not inevitable. They subsequently described how people could survive and why testing was a necessary part of this process.

Survival

While all 15 participants used language that clearly linked being HIV positive to dying, most participants personally felt you could survive and live a long life even if you were positive. In fact, a frequent phrase, stated explicitly by six of the participants and implied by 6 others, was that HIV and

AIDS[15] "not the end of the world." This phrase was stated so emphatically at times that it was clear participants were responding to messages to the contrary. To elaborate on this belief, many participants stated that you could live with the virus for "plus minus 16-20 years" (Sipho, 23-year-old male) or you could even "live for 25 years, 30 years with HIV" (Vusi,21-year-old male). Some even ventured to say,

> *You can achieve greater achievements than the person who's negative and you are positive. You can achieve beautiful things. Do things for yourself. Go out there and get what you want (Sipho, 23-year-old male).*

Another participant had similar feelings, stating that

> *He or she [who] has the virus on her body...she is still the same, she can live longer than the person who is HIV negative...a person [who] is HIV positive can live longer than a person who is HIV negative (Xola, 20-year-old female).*

Also comparing an HIV positive status to an HIV negative one, one participant explained,

> *You can live with HIV, you understand, and you can die without it (Vusi, 21-year-old male).*

Healthy Living

To support the belief that an HIV positive person could live a long, healthy life, sometimes even longer than an HIV negative person, participants explained that surviving required that HIV positive people took care of themselves. Participants spoke of lifestyle changes that HIV positive people could adopt in order to stay healthy. Maintaining a healthy diet, exercising regularly, using a condom during sex, and being surrounded with supportive people were all important elements in taking good care of one's self. These elements were often spoken about in succession. One participant talks about the life changes that one undergoes after a positive diagnosis.

> *Hannah: If you have HIV, if you test and you're positive, what is the next step in your life?*
>
> *Sizwe: Eish. I feel that the next step would be (clears throat), a next step would be on how you would treat yourself.*
>
> *Hannah: Ok. Tell me about that.*

[15] Some participants distinguished between "HIV" and "AIDS" while others used the terms interchangeably. In this instance, both terms are used because participants' responses included both terms.

Sizwe: How you will handle yourself. If you have sex, use a condom. Eat healthy food. Exercise regularly. Talk about it. Support those who have it (Sizwe, 20-year-old male).

Another participant included some of these elements in his explanation how HIV positive people can stay healthy.

Hannah: What are things that people do when they are HIV positive? To stay healthy?

Bulelani: Ok, Hannah. If they, if they eat vegetables, yeah, eat vegetables...Also talk to people, be happy, don't stress yourself, but not to hurt. It can also help stay positive (Bulelani, 25-year-old male).

Diet, exercise, and staying around supportive people were emphasised frequently.

As a positive person, like, you keep, can look at your health eating and exercise. Try to be as positive as possible. Like, sit around people who will not judge you but give you advice...So you need to be associated with people who are positive about life regardless of any disease or any disorder that you may have (Sipho, 23-year-old male)

In addition to a nutritious diet and exercise, many participants stressed that drinking alcohol and smoking were damaging to the health of HIV positive people and they should be avoided.

I think immediately...at the clinic and they give you the instructions...and they tell that you must limit drinking alcohol and smoking (Vusi, 21-year-old male).

These instructions were sometimes combined with messages about safer sex practices, most commonly condom usage.

No drinking, I think, too much alcohol, unprotected sex. They say if you are positive you can try to eat healthy and exercise (Andiswa, 25-year-old female).

Maybe you have to condomise first. And you don't have to sleep with so many guys all the time. You have to eat vegetables, fruit, and also juices. Also do training so you can become strong. And don't do drugs like drinking alcohol and all those things. And you also have to go to the clinic sometimes to check you CD4 counts (Lindiwe, 25-year-old female).

Antiretrovirals

While much of caring for one's self involved eating a nutritious diet, exercising, thinking positively, and wearing condoms during sex, the prospect of receiving ARVs after a positive diagnosis was seen as the key to survival. Participants spoke of the benefits of ARVs for the health of HIV positive people.

There are pills I believe, that you can use for, like, protection from the other diseases like, what are they called? ARVs. I'm not sure. They are pills that you can, I don't know where they are sold or not, but you can use the pills. I don't have full knowledge about those pills but all I know is that they are really helpful because I think they boost the immune system (Dumisani, 20-year-old male).

They are drugs. And they reduce some, maybe if you can't wake up from the bed, at least they give you so much energy so you could pick up (Philani, 19-year-old female).

I think ARVs like it's the ... retrovirus like they are pills like which help the immune system of the person who is HIV positive help to be stronger. I'm not sure I think it reduces like the virus like from spreading more, more and more into the body (Xola, 21-year-old female).

ARVs were seen as a way to combat death, shown by some participants who explained that ARVs could keep you from dying.

What I know definitely for sure that about AIDS kills, you understand? But my knowledge about AIDS, AIDS it is very dangerous, very dangerous especially for those people they don't get the treatment (Vusi, 21-year-old male).

If you take [ARVs] the right way it will work. They will help you but it's not a cure. It's just a treatment for you to get better (Sethembile, 19-year-old female).

Because the thing that is happening now you know because there are many people that is HIV and AIDS, if you go to the clinic you will get some treatment and will go to be better (Zanele, 23-year-old female).

A few participants included their own experiences of witnessing the successes of ARVs for people in the areas where they lived.

I think ARVs are good because, there were people in my community, you see. Others are, have passed away, others are still alive. The ARVs have helped them a lot. Others were thin as this pen. But when they ate ARVs they were back to this, 150kgs of weight. You see? You see? (Sizwe, 20-year-old male).

One respondent spoke about ARVs as being the only way to survive being HIV and that is was imperative for people to take them if they wanted to live.

Since there's no cure for AIDS I think people should stick to the ARVs 'cause they're the only medicine here in the world that we have. And it's affordable. If they still need to live, if they are still more things in life they need to do then there's a chance to think about, there's a chance to take ARVs. Cause it's the only way (Philani, 19-year-old female).

Importance of testing early and often

In explaining that a person that could still live even if they were HIV positive as long as they were taking ARVs, participants stressed the importance of knowing your status, thereby making ARVs a major motivation for HIV testing. Knowing one's status through HIV testing was seen as a preventative measure against getting sick and dying from AIDS. Participants expressed two main points about HIV testing. Firstly, when asked to talk about HIV testing, virtually every participant stressed the importance of knowing one's status and asserted that everyone should be tested for HIV, with some even explaining that people should test regularly.

> *I think everyone has to be tested (Dumisani, 20-year-old male).*

> *People must go test. I think you test twice a month, I mean, twice a year because every six months (Sethembile, 19-year-old female).*

Secondly, participants believed that it was always better to be tested sooner rather than later. Numerous participants made this point clear by explaining that if a person found out his or her status in the advanced stages of HIV, then it was difficult to reverse progression of the virus and become healthy again.

> *Sipho: Being able to understand your status at an early age so that you can be able to take good care of your body at an early age rather than finding out at the last moment while the virus is already in your body and there is no way you can stop it. That's the worst thing one can ever do to herself. The sooner the better for people who will come up positive. And the gooder the better for those who will be negative. It's good to be earlier than late.*

> *Hannah: Tell me about that. Why is it better to be earlier than later?*

> *Sipho: I think for me, being able to know your status early on, it's more of an advantage than knowing later on that you are HIV positive because you might have wished that so many maybe years or even months for them to take care of like, the swelling and viruses that have aggravated and doing something big but you could have cured it while it was still in the developing stage (Sipho, 23-year-old male).*

Likewise, the next example of one participant's personal testing story stresses the importance of tested early to avoid the physical threats posed by being HIV positive.

> *Hannah: Have you ever been tested for HIV?*

> *Zolani: 3 times. Also I want to get tested even now.*

> *Hannah: Hmmm, so you do it?*

Zolani: After 6 months I do have, I get tested.

Hannah: That's great!

Zolani: Because I want to know my status. I don't want to die.

Hannah: If you know your status, how will that make it so that you don't die? If you know it?

Zolani: Like it is good to know you have HIV before you get sick. So that your CD4 count cannot be low (Zolani, 21-year-old female).

Another participant supported this point of testing early by explaining that there were dangers to not knowing one's status and only once someone had tested could they access ARVs.

Nobantu: And the other thing is, not knowing your status is very dangerous. You just find yourself you're already AIDS. And then not HIV now.

Hannah: And if you know your status, what can you do about it?

Nobantu: Go to the clinic and ask for ARVs or the pills that just can, as you can stay normal, you see? Not get sick (Nobantu, 20-year-old male).

The one participant who was currently taking ARVs at the time of her interview strongly advocated starting ARVs as early as possible in order for them to be effective. She explained that many people died because they did not start taking them until they were very sick. This led to deadly consequences.

I think that they are beneficial to all the people because they can save someone's life. If there are more people taking them earlier, know about them earlier, when its time to take them, they know that they are supposed to take ARVs. They go for ARVs so that...so that there can be less of children without parents. And even maybe you've got a brother or sister, you want to stay with your brother or sister as long as you can, you know (Kwanie, 31-year-old female).

The need to start treatment before one is too sick with AIDS is echoed by this next participant, who was speaking about her feelings of ARVs.

I think they are a good thing because like let's say I'm HIV positive and like let's say I find out like it's been a year that I'm HIV positive but like there are no symptoms in my body that HIV positive. And then like they put me through ARVs and like I'm not willing to take them, I don't want to take them. I think like as time goes by like my immune system like will start to die or something and then like if they put me like at a later stage like it's been far too long for me like to take ARVs. I think it would be like hard for my body to accept like I don't

know...the virus is already like spreading it's much, much more and I think it will take more time to work than if I have taken them earlier (Xola, 21-year-old female).

The link between AIDS and survival through the uptake of ARVs as well as the importance of testing early are highlighted by one participant's explanation for her own reasons for testing for HIV.

I think I want to know that I am clean or not so that if I am not clean I can start taking, like pills, so that I can survive but I think if you found out later, it is not. If you found our later it is not like when you found it earlier, because there are ARVs. If you found out now maybe you can find out this year and you start taking ARVs maybe three years later. Some of them they found out right now and they don't even have HIV, they got AIDS on it own (Andiswa, 25-year-old female).

In this story, the participant repeats the common belief that if people wait to test until they are sick with AIDS, there is very little that can be done.

4.2.3 Summary of Findings

This section first revealed the physical threat that HIV poses on HIV infected individuals. Opportunistic infections (OIs) and death from HIV were clearly salient to the participants. Although only two participants were HIV positive and only one had experienced AIDS-related illnesses, all 15 people in the study had learned about HIV or experienced HIV with friends and family members. This led them to believe that the opportunistic infections and eventual death were not inevitable, provided that HIV positive people took care of themselves. ARVs were an essential part of this care. Also essential was finding out one's status, and the sooner a person knew the better. In one participant's words, "It's good to be earlier than late" (Sipho, 23-year-old male). This was primarily because HIV testing was crucial in initiating ARV treatment and practicing other means of healthy living. The participants were also acutely aware of circumstances where people had only tested for HIV when they were very sick, and were therefore unable to recover from the disease. The physical threat of HIV was believed to be controlled or managed through HIV testing, where opportunities for treatment and care became available.

4.3 Social threat

And you find then they saying, I wish the earth could open up and swallow me so I couldn't be in earth anymore (Sizwe, 20-year-old male).

The second threat that participants highlighted was the social damage that HIV positive individuals were exposed to when they tested positive. The social threat stems from public disclosure of one's

HIV positive status and the resulting isolation, gossip, and blame. Participants explained that once a person was diagnosed with HIV, he or she was treated differently by friends, family members, or the community. They subsequently discussed the reluctance to get tested for HIV for fear of the reactions and possible abuse by family members, friends, and the community. Participants also explained that while HIV tests were meant to be confidential, testing was often avoided because it was difficult to hide one's HIV status after being diagnosed positive. Exemplifying the effect of social threats on HIV testing, participants demonstrate that when individuals perceive a strong social threat to being HIV positive, they are deterred from testing.

4.3.1 Perceptions of the social threat

Participants explained their perceptions of the numerous social threats that HIV positive individuals were exposed to when others were aware of their status.

Avoidance and Labelling

There was a perception that HIV positive individuals became isolated due to the fact that people were afraid to be around them for fear of catching the virus. Although participants explained that these fears were unfounded because HIV could only be transmitted through blood or unprotected sex, there was still a perception that this fear existed in other people, subsequently leading to isolation and avoidance of HIV positive people. One participant discussed her personal feelings about HIV when she heard the word spoken.

> *Oh, scared. Yeah. Because, um, some people, you see, when you have HIV they even, they don't even want to sit next to you it's like, when you're sitting next to them then they're going to become HIV positive (Sethembile, 19-year-old female).*

Another participant described how HIV positive people were treated in the area where he lived.

> *Dumisani: Ok, um, ok. Many, many, many people from where I live, hey, it's, the thing is, when you have the disease, they tend to isolate you. Like, they don't want to associate themselves with you.*
>
> *Hannah: And how do they do that?*
>
> *Dumisani: By trying to avoid you. Like, when you come, they will go away. They don't want to talk with you (Dumisani, 20-year-old male).*

Similar to these two participants, another girl described the labels placed on people who are infected with HIV.

What I've seen happening, like where I live in, there are some people who are labelled, as a flag they are; they have HIV (Xola, 20-year-old female).

Rather than highlighting how HIV positive people were actively avoided, however, this same participant described the disrespect and discrimination HIV positive people experienced because of their label.

It's like, Hannah. Let's say we don't agree about a something, a silly thing, and then like you tell her like, if you don't like what I said or something, then I said I won't listen to you. If, like, let's say you are HIV positive, I won't like, I won't want to listen to what you are saying. It's like you are wrong; you are dirty or something there's something wrong with you; you are not as equal as some other person. Ja (Xola, 20-year-old female).

There was a strong perception that HIV positive people were avoided by friends, family, and member of the community.

Rejection

In addition to isolation and avoidance one of the most prominent reasons given for why people were afraid to know they were HIV positive was because they would not be accepted by their friends or family members. Participants gave examples of people they knew who were rejected by partners after revealing their status. One participant explained the reaction of her sister's boyfriend after finding out that she (his girlfriend) was HIV positive.

Because her, first thing that her boyfriend dumped her (Zolani, 23-year-old female).

Another participant also explained his belief that it was difficult to disclose one's status to a partner because of the fear of rejection.

So you try to tell your partner, as you can see. It's hard. It's very hard. Just because they kick you, they could kick you out of the house, you see (Nobantu, 20-year-old male).

Other participants specifically cited the family as the source of rejection.

Some of them are scared what their results may be...and maybe their family wouldn't allow them (Sethembile, 19-year-old female).

Another participant explained how important it was to be accepted by one's family and why the fear of being rejected often caused many people not to disclose their status or even test. Here, this participant speaks about the difficulty of being HIV positive.

Hannah: What are the things that make it difficult to accept being HIV positive?

Andiswa: I think she or he doesn't know the response of his family. Maybe they are going to accept him or not. Maybe they are going to support her or not because if you don't have the support of your family, it is not a good thing (Andiswa, 25-year-old female).

In addition to a lack of acceptance by partners and family members, other members of the community also contributed to the social threat posed on people who were HIV positive. Rejection and judgment from the community led many people to resist finding out their HIV status.

Hannah: What are the reasons why you would know what to know that you had AIDS? Or not want to know your status?

Bulelani: Some, they are afraid of the community. Some of them, you know, they talk a lot, you know. For example, if you've got TB, yeah, TB is also dangerous, serious. If you've got TB, they thought that you have AIDS. That is why some people don't want to get tested. Yeah, some be judging you. Yeah, they didn't console you (Bulelani, 25-year-old male).

Another participant discussed the judgment HIV positive felt was placed on them by others, as well as the rejection by family members.

Philani: And some of the people don't feel comfortable being HIV. And they are afraid, yeah. To speak to others cause they think they would be judged by others.

Hannah: Do people get tested?

Philani: Yeah. Some of them. But not all of them. Cause they are scared.

Hannah: What are the things they could be scared of?

Philani: Maybe you could be an open person. Now you are HIV. Now you are telling someone that you are HIV. The thing that you'd be scared of is being laughed by those ones you told that you are HIV positive. And maybe dumped by your family. Yeah. And being alone (Philani, 19-year-old female).

Rejection or lack of acceptance by family members was highlighted repeatedly and was shown to be one of the primary fears of living with HIV.

Blame and personal responsibility

An HIV positive status was often associated with blame and personal responsibility. Participants explained that when fault was attached to being HIV positive, people were afraid to reveal their status to others.

Like in most cases people they don't, [people are] still blaming those people who are HIV positive. They were not faithful enough to their partners. Like, if they saw somebody positive maybe some of them they are laughing at them and they're saying nasty things about them (Andiswa, 24-year-old female).

Another participant linked the gossiping of one's family to the blame of being positive, showing how the potential social threat of being HIV positive can lead individuals to disclosing their status.

'Cause they can get tested and tell their families, maybe from the family you've got a friend. Now you are sitting together, there's this thing. Now the person says the things that he shouldn't have said. Yeah. So it's, the thing starts from there, like the person who's HIV, maybe he or she thought she was doing the right thing by not to tell others, to tell the family only. But you will find some families there's been, there are some families that are rude. It you've done something wrong, they say that you are like this. How can you do such a thing like this? Don't you know that you are HIV? Maybe everyone know that you are HIV and now you are, today there's this car in front of your door and tomorrow there's this car. And people will say, 'How come there's a lot of cars? That's how come she's HIV. She freaks a lot.' Yeah, things like that (Philani, 19-year-old female).

In these two instances, blame for being positive came from family members, sexual partners, and other members of the community.

Gossip

Gossiping about HIV positive people was cited by 10 participants to be a common occurrence in the areas where they lived. Gossip served both as a means of passing judgment and way for spreading information around a community. Gossip was seen as the reason why it was difficult to keep one's status a secret.

And, and the community, the way the community, the people they is going to look at her, you understand? It's like people they are going to gossip about her: 'Have you heard that Vusi is affected with HIV/AIDS?' (Vusi, 21-year-old male 34)

Some accounts of gossip were scornful and reinforced the link between HIV and death.

Hannah: What do you hear when people gossip?

Zolani: Yeah, (in a gossiping voice) 'she's she has HIV, she is going to die!' (Zolani, 21-year-old female).

Another participant reported how gossiping exposed a person's status to others.

It's just that people are saying things that 'She died of this.' 'She's suffering from it now.' Yeah. I think it's something like gossiping...There are a lot of things happening. There's a lot

of gossiping.... Even if you are walking down the street, people are pointing at you (Philani, 19-year-old female).

Linking back to the isolation and avoidance discussed in the previous section, one participant explained how gossip can expose an HIV positive person to isolation and avoidance.

Hannah: And why do you think they don't want people to find out?

Xola: Because like what I think is because like as we are kids growing up if like I found out that like my friend maybe is HIV positive like and then like she tells me and then I tell another person, that person like will take the wrong way and then won't want to be in contact with that person saying that she is positive and all those things and like she will infect her or something (Xola, 20-year-old female).

Gossip facilitated and reinforced the social threat of living with HIV because it allowed for the spread of information regarding someone's HIV status. In addition to this, gossip was often laced with blame and could lead to the avoidance or labelling of those who were HIV positive.

4.3.2 HIV testing as exposure to social threat

Unlike the physical threat created by HIV, the social threat experienced by HIV positive individuals discourages testing. As can be seen in the examples presented above, participants expressed the damage caused by other people knowing you were HIV positive and the subsequent desires of many people to avoid the isolation, gossip, rejection, and blame of being HIV positive. While it would be reasonable to assume that HIV testing itself does not expose individuals to the social threats associated with being HIV positive as VCT is presumed to be confidential, the next two themes explain how participants often perceived disclosure of status as an inevitable consequence of HIV testing. These themes will be used to further substantiate the claim that HIV testing is directly linked to exposing someone to these social threats.

Confidentiality and Nurses

Firstly, participants spoke frequently about the experience of getting tested and how counsellors or nurses at clinics gossiped and judged HIV positive people. This meant that even if HIV positive individuals did not disclose to other people such as friends or family members, they were still blamed for contracting the virus, their status was not kept confidential, and the community often found out they were HIV positive. In explaining how nurses gossip, one participant said that people often seek health care from clinics that are far away from where they live.

They don't want to um, some of them um, maybe they go test, you see, and then they go to the clinics maybe someone go to the town, you see, because they're in the clinics here, here in KTC, maybe some of them know the nurses there that gonna [test you], you see, and they ashamed of themselves. They say maybe that nurse will tell the people that oh, that, 'she's HIV positive' (Sethembile, 19-year-old female).

Another participant described her own testing story and the fear she experienced while waiting for her results because the nurse who was counselling her knew her family.

Lindiwe: And the person that was counselling people, like she know about my surname and then she was asking are you living, ok do you know who and who? And like, my heart was (motions that it is beating fast) and then what if you are positive? Who, do you want us to call? Your mother, who's the, who are you going to tell, the first person? And then I said my sister. And then they say no, you are negative.

Hannah: Do you think she told people?

Lindiwe: That I am negative? No, but I think if I was positive, she was going to tell someone. Even if it's one people, she was going to tell. Do you know? (Lindiwe, 25-year-old female).

During her interview, this participant explained that she was thinking about getting tested again and she wanted to go to the clinic she was working but was warned against it by a friend who stated that if she was positive, the nurses at the clinic would gossip about her.

Lindiwe: I even wanted to test today but Andiswa said 'no you don't have to test here, at least you must go to the other clinic.'

Hannah: And why did she say that?

Lindiwe: She say, like, we are working here, maybe I can just test, maybe I can become, like, positive. Maybe the one that told me can just tell her friend 'do you know that she is positive?' And like all those things (Lindiwe, 25-year-old female).

Participants perceived health care workers administering HIV tests to be untrustworthy. They were afraid of being judged and they feared that if they were diagnosed with HIV, the nurses would gossip about them at the clinic or in the communities where they lived. This judgement and gossiping by the VCT nurses meant that testing could expose one to social threats even if they did not disclose their own status to friends, family, or the community.

Being seen at a clinic

The second reason participants equated an HIV test to a disclosure of status, and the subsequent social damage that followed, was that being seen at a clinic often signified that one was HIV positive,

regardless of the actual test result. This was especially true in situations where the clinic had a special section for people who were testing for HIV or picking up their ARV medication. Thus, people resisted testing for HIV because others would see them at the clinic and proceed to gossip and stigmatise them. In one instance, a participant explained that merely testing for HIV caused others to gossip even if the test came back negative.

> *Some of them, they don't want to go to the clinics. And be seen by, maybe let's say you are my friend and I saw you going to test. Yeah [they want it to be private] because if someone saw you, that you go for testing, and maybe next week you've got cough, they say you've got HIV. They don't think that maybe it's just the flu (Bulelani, 25-year-old male).*

Another participant explained why his friends did not want to test at their local clinic. They feared that news of their status would spread quickly around their neighbourhood.

> *[My friends said], 'I'm not going to do it in our local clinic. I'd rather go pay because the people here, they will tell you that you are HIV positive, and then when you get home, everyone knows about your status. That you are HIV positive' (Sizwe, 20-year-old male).*

In addition to discouraging testing, some participants spoke about how some people were afraid to pick up their ARV medication from the clinic for fear of being seen by others. The clinic in this participant's neighbourhood had a clear section for HIV positive people.

> *I think they are scared you know, or scared about the, about some other people seeing them to go to the clinic and take some tablets because in Nyanga clinic here there is a side for people that have HIV/AIDS. And everybody is knowing that side so I think some of them they are scared to see that yhu! Maybe Xola saw me that I'm going to eat that tablets, you see? (Zanele, 23-year-old female).*

The fear of complete disclosure when picking up ARVs from the clinic is also echoed in this participant's explanation of why some do not seek medical care at the local clinic for being HIV positive.

> *And like in the Crossroads Clinic it's like people from were I live, like, around the community and then if they come, like a person like my age, I'm HIV positive I go for treatment there. Then I see someone of which I know maybe a person who is older than I am, then if that person see me like in the same queue as she is or in the, like, people who go for HIV they know their rooms which they are going. And then if someone sees me that I'm going through that room I'm going for my HIV treatment and they know from that day that I'm HIV positive. And then after that I hear people telling that they seen me in the HIV side going for treatment bla, bla, bla. And some, they don't want to go for a treatment, like, they will be, like, sharing their status to the whole world if they go to a clinic and go for ARVs or something (Xola, 20-year-old female).*

When participants were not worried about nurses revealing their status, they explained that simply being seen at a clinic could facilitate the spread of rumours or gossip. Testing was either avoided or navigated very carefully, such as the circumstances where people would travel to town to get testing for HIV.

4.3.3 Summary of Findings

The social threats of being HIV positive were very salient to the participants in the study. The rumours and labels attached to people who are infected with HIV led participants to fear disclosure of an HIV positive status, which they believed was the inevitable consequence of diagnosis. Witnessing the rejection by partners and family members that many HIV positive people experienced further solidified the damaging effects of the social threats of being openly HIV positive. Personal experiences of the powerful impact of gossip and the lack of confidentiality in the testing process caused participants to mistrust nurses, counsellors, and testing services at local clinics. As shown, one participant's portrayal of the effects of social stigma highlights the utter desperation many HIV positive people experience: "I wish the earth could open up and swallow me so I couldn't be in earth anymore" (Sizwe, 20-year-old male). In an effort to avoid these negative social threats, individuals are often discouraged from wanting to test for HIV.

4.4 Psychological threat

I think they are some they are scared...like a friend of mine like she is saying like don't want to do... To dig a rock which is closed to find out something that she's not prepared to hear about (Xola, 20-year-old female).

The third perceived threat individuals are exposed to when they learn of their HIV positive status is the psychological damage created by knowing that they are infected with a stigmatised and life-altering virus. While much of the psychological and social threats of being HIV positive stem from similar sources of isolation, blame, gossip, and lack of acceptance, participants in this study made clear distinctions between the damage created though public exposure of status and the internal breakdown that occurred after learning one was HIV positive. This was explained both through the reactions of HIV positive people to learning about their status and also by the suggestion numerous times that it was sometimes better for HIV positive people not to know about their own status. In fact, repeatedly throughout the interviews, participants stressed the damaging, often deadly, impacts that negative thinking had on the outcomes of HIV and AIDS. Like the social threats of being HIV positive, psychological threats also discouraged HIV testing.

4.4.1 Perception of the psychological threat

Participants explained the numerous psychological threats that individuals were exposed to when they discovered their own HIV positive status.

Mental destruction

In probably the most illuminating indication that being diagnosed with HIV has the potential to lead to psychological damage, many participants reported deep internal destruction that stemmed from a positive test result. Though certainly linked, this internal damage was distinctly different from the physical symptoms associated with AIDS and from the social shame and rejection of other people knowing one's status. One participant clearly shows this in his explanation of the impact of AIDS.

> *I don't know how to put this, but, the impact that AIDS is making in a lot of people's lives is it's destroying them, like mentally more than like physically so that's why they are demotivated (Dumisani, 20-year-old male).*

Another participant also alluded to the difficulty many people face when they learn that they are HIV positive. In this instance, being "demotivated" was expressed through desperation of not being able to handle a positive test result.

> *Some they don't know how they are going to deal with this, you understand? (Vusi, 21-year-old male).*

One participant explained that it was difficult to predict how one would react to learning of an HIV positive status. She highlighted the pressures that were placed on HIV positive people to "be positive" or "talk openly" about their status but explained that these were unreasonable expectations.

> *Andiswa: Some of them don't accept it and I think we expect too much from people who have HIV. We don't know the pain of being HIV positive but I think we expect too much from them.*
>
> *Hannah: What do we expect from them?*
>
> *Andiswa: I don't know whether it is easy to tell somebody else. It is because, right now I don't know whether I am positive or I am negative. Maybe right now I think I am strong. I think that if maybe tomorrow I can find out that I am positive. I thought I am going to tell my family but when that time comes I don't know whether I am going to be strong...That it is why I am saying that we are expecting too much from those people and we don't know the pain (Andiswa, 25-year-old female).*

The observation of people in their lives who were depressed because of their HIV positive status coupled with the concession that they could not fully understand what it felt like to be positive made participants strongly aware, and afraid, of the mental destruction that could surface after being diagnosed with HIV.

Lack of personal acceptance

Similar to the rejection by friends and family members, participants reported that those who were diagnosed with HIV often failed to accept themselves and their own status.

> *And I think HIV like it's a very big problem in our community where I live in because like there are many people who are infected with it and some of them do know that they have HIV but it's hard for them to accept it (Xola, 20-year-old female).*

One participant even explained the dangerous impact of not accepting one's own HIV status. This participant had two uncles who were living with HIV and he showed how personal acceptance of status proved to be the difference between life and death.

> *The one who is still alive, yeah, the main reason he's still alive is he did accept that he's gotten AIDS. And he used to drink but he stopped. He didn't smoke. He didn't smoke. The other uncle, he didn't accept it. And he ended up dead (Bulelani, 25-year-old male).*

In another example of the implications of not accepting one's own HIV status, one participant described what it was like to live with her sister while she dying from AIDS-related illnesses.

> *Hannah: What was it like to live with her when she was dying?*
>
> *Participant: Ah! It was sad. Because I see her suffering, slow ... Her life was just miserable. She didn't accept it. Accept it (Zolani, 21-year-old female).*

Lack of personal acceptance was seen as a psychological threat that an individual experienced by being HIV positive. Although clearly not an inevitable part of living with HIV, demonstrated by contrary instances of acceptance of one's status, participants perceived this to be a common outcome of a positive diagnosis and were aware that this threat could lead to suffering and death.

Stress/negative thinking

The psychological threats of depression and isolation brought on by learning that one was infected with the HI-virus were often transformed into heightened physical risks. For example, an HIV positive diagnosis was believed to cause a lot of stress on an individual. Stress was overwhelmingly

seen to have a negative effect on someone's health and could expedite death. One participant explained the impact of stress on the immune system.

> *Most of the time your CD4 count is also about stress, stress makes your CD4 count drop (Noneka, 23-year-old female).*

Another participant showed the damaging effects of stress by giving an example of how and why his two siblings died of AIDS.

> *Because my brother and sister passed away at an early age...they had too much on their mind, worries, things that they could have wished to have done in their lives but now that they will never be able to do it again. I think that's one of the ways that made if worse for them to pass on. Like actual physical level. It was, like, hurting them emotionally, there was no way they could have things straight. So in that way, they lost weight and all that stuff, like, all the symptoms can gather on one position (Sipho, 23-year-old male).*

Living with HIV could cause stress in a person's life and this stress was often seen to cause undue harm.

Shame

Three participants explicitly suggested that people were afraid to find out they were HIV positive because they were afraid to admit that they had knowingly exposed themselves to HIV. Blame assumed that HIV infection could have been avoided. In these next two instances, the family was the source of blame and the message appeared to be saying "I told you so." Rather than demonstrate a social threat, however, these instances demonstrate the internal shame of having made an unwise decision. One participant explained why people hide their HIV status from their family.

> *Hannah: What are the reasons to hide that you have HIV?*

> *Vusi: They know that I won't get support from my family, you understand? Maybe she was fooling around and now, and their parents, they are trying to stop her on that, for doing that. So she afraid, she will be afraid not to come, to came back to tell their parents now I'm HIV, you understand? She will know that my parents will say to her you, 'now we told you that you must stop doing this.' So I think that's one of the reasons for people to hide this (Vusi, 21-year-old male).*

The other participant used this same explanation to show why people did not want get tested.

> *Like, some of the parents are strict, like ok 'Don't do this, do this' But when you're older now you say 'I'll do this, I'll do this.' But your father did tell you not to do this or you will get HIV*

and AIDS. Sometimes you are going to be too afraid to tell your parents, you see (Nobantu, 20-year-old male).

Learning that one was HIV positive despite also knowing the dangers of HIV and the methods for HIV transmission and prevention was perceived to result in internal shame.

4.4.2 HIV testing as exposure to psychological threat

Unlike the physical threat (but similar to the social threat) created through being HIV positive, the psychological threat experienced by HIV positive individuals discourages testing. Depression, isolation, and mental breakdown were some of the damaging effects of learning that one had HIV. With clear links between psychological threat and HIV testing, it is not surprising that the test was often consciously avoided. To further support the impact that an HIV test had on exposing individuals to the psychological threat of being HIV positive, participants discussed the harmful reactions that many people had to a positive test result. Profoundly, participants then stressed that it was sometimes better not to know that one was HIV positive.

Reactions to test result

Participants frequently discussed the reactions of people who learned they were HIV positive. Withdrawal from normal activities, depression, and "giving up" were cited, shown specifically in this statement by a participant.

> *'Cause maybe you were an active person and now you are the best in community. Now there are things that now you are doing, now you are not doing. Yeah. Maybe you are a star, let's say so. Since you heard you are HIV, now you are not interested to continue in what you were last. Yeah (Philani, 19-year-old female).*

Two behaviours in particular highlight the internal collapse and fear that are associated with being diagnosed with HIV: spreading the disease and committing suicide. In the following two examples participants gave of HIV positive people spreading the virus after learning of their positive test result, there is clearly a fear of being alone attached to living and dying with HIV.

> *When you talk to most of the people, they think that they just told them I'm HIV, I'm going to die soon so let me rather spread this disease and not use condoms...Most of the people do that. They tell you they won't die alone and we will all die together (Noneka, 23-year-old female).*

The second participant was speaking directly about his friends and their fear of getting tested for HIV for fear of dying alone.

Some of them they say...all of my friends and me talk about it, you know. And he said that if he found out that he has AIDS, he, she, he will spread it. He will love a lot of girls. He didn't want to die alone. That's what he says (Bulelani, 25-year-old male).

The other common response to being diagnosed HIV positive was to commit suicide. This was cited by a number of participants and highlights that utter despair and psychological damage people experience after learning their status.

Nobantu: And they are afraid of their results too. Afraid of the results.

Hannah: And what do you think actually happens when people get tested?

Nobantu: Some of them, they just commit suicide. Commit suicide (Nobantu, 20-year-old male).

One participant cited suicide as the result of people losing self control or becoming overwhelmed by an HIV positive diagnosis. Throughout much of his interview, this participant also talked about the frequency with which HIV positive people drank alcohol and he stressed the deadly impacts it could have on someone's health.

Because most of the people when they get affected on this they become, they loose their self control...I don't think that's a good idea if you know that you are affected by AIDS you should kill yourself, you understand? There are lot of things you can still do rather than killing yourself...There are a lot of people they did that. And some, they are mixing a poison, drinking a poison, you understand? Some people they just think it is the end of the world, I rather drink until you die, you understand? (Vusi, 21-year-old male)

Another participant linked the physical threats of HIV to psychological threats, stating that suicide was a reaction to AIDS sickness.

Hannah: So how do you think most people found out they are HIV positive?

Noneka: Some of them they find out that they are sick. If can be any kind of sickness...

Hannah: And when people are sick like that, what do they do?

Noneka: They go to a clinic. To get treatment. They kill themselves (Noneka, 23-year-old female).

One participant bluntly stated that some people actively resisted getting tested for HIV because they knew if they were diagnosed positive, they would kill themselves.

But some, they don't want to find out. They know that if they find out they got AIDS, they just kill their selves (Bulelani, 25-year-old male).

Better not to know status

In a follow on to the harmful psychological reactions that participants believed followed a positive diagnosis, many of the people interviewed in this study strongly believed that sometimes it was better not to know that one was positive.

Hannah: Do you think it's better to know or not to know that you are positive?

Philani: Um, it depends. Cause, um, if you think that it's better to not know in yourself, as maybe you don't know if you're HIV, maybe you are getting sick, now it's time for you to go and check. And now you are found out, I'm HIV. What am I going to do? I'm still at school. What are the kids going to say about me? Now, I'm losing weight. I'm like this and like that. And yeah (Philani, 19-year-old female).

Similar to the participant who expressed the difficulty in being able to "deal with" a positive diagnosis, this example presents the question 'What am I going to do?' Also, although this participant highlighted specific situations, such as school, which present a social threat, the recommendation that it was "better to not know in yourself" (rather than simply not disclosing) substantiates the psychological threat. A parallel example also highlights the dual impact of social and psychological threats. In this next example, the participant was asked whether or not people should know their own status.

That's quite a difficult question you are asking me. You have to choose either way you think it's right for yourself. You think that not going to find out that you are HIV positive is fine. It is going to take away the thoughts that – you know if you know something, you are the only person who knows about it. And you know you want to tell someone but you are scared. But when people look at you, you think that they know because you look that thing (HIV), you know? So now in your mind you start to think that people, in the way they treat you, 'oh they know that I'm HIV positive; that is why they are treating me like that' even though you haven't told them. You just assume all the things in your mind (Kwanie, 31-year-old female).

This same participant continued by echoing the belief that sometimes it was better not to know that one was HIV positive. She connected the social stigma and blame associated with HIV and AIDS to the psychological damage of internalizing the shame of infection.

Because I have seen people like getting sick and like they knew. They knew that they are sick. They know what they have got. They did not want to go and find out that it's really true because they are thinking of the things that has been said...People are going to think, oh, it's better you don't know. So that you don't have that shame (Kwanie, 31-year-old female).

Two further examples suggest that the psychological threats posed on an individual who learns that he or she is HIV positive can discourage HIV testing. Like many participants explained, these two examples highlight the fears that many people have that they will die if they test positive for HIV.

> *Zolani: Like my friend. I do have a friend, before I was having my daughter. I told her that I am going to the clinic, like there is a free testing but she did not want to go with me.*
>
> *Hannah: She didn't want to get tested?*
>
> *Zolani: I asked her why. She said 'no, I don't want to know about my status.' I said why? She said 'no, I am going to die' (Zolani, 21-year-old female).*

This next participant explains that if people test for HIV and the results come back positive, they may die earlier than they would have had they never tested in the first place.

> *Bulelani: Some of them, they did not want to know their status. And some of them say that 'I don't want to die early.'*
>
> *Hannah: If you go get testing, why does that meant that you will die early?*
>
> *Bulelani: So if you test, and you have HIV, and you don't accept it, you will die early. You will end up doing things that you shouldn't do. Not talk to people, stay alone, don't want to see anybody – even your family. [And these things make you die early] (Bulelani, 25-year-old male).*

4.4.3 Summary of Findings

Fear and resistance to test for HIV can be linked to the perceived psychological threats that one could be exposed to after learning that he or she is HIV positive. Although only two participants were living with HIV, most of them discussed friends or family members who were infected with the virus and therefore had personal knowledge or experience with the depression, internal shame and rejection, and stress that sometimes accompanied living with HIV. In addition to portraying these experiences as deeply painful, depression and stress were also seen to exacerbate HIV infection and could lead to a quicker death. When psychological threats were demonstrated through thoughts of suicide, participants even suggested that not knowing one's status was sometimes advisable. Thus, the perceived psychological threats that were presented through personal awareness of HIV status were linked by the participants to the low levels of HIV testing in South Africa.

4.6 Discussion

The three threats above – physical, social, and psychological – have variable effects on HIV testing. Physical threats, which are mitigated through testing, encourage VCT. Social and psychological threats are actualised through HIV testing, and therefore discourage VCT. This discussion will look at these findings by drawing on the related literature from Chapter 2.

In corroboration of the academic literature articulating an HIV test as the gateway to both prevention and treatment interventions (UNAIDS/WHO 2004), the empirical findings in this study suggest that participants were also supportive of HIV testing for the achievement of these two goals. In the first instance, participants explained how an HIV test could lead to increased condom usage, regardless of whether the test result was positive or negative. Although the link between knowledge and behaviour has been critiqued in the literature (Campbell 2003; Hutchinson and Mahlalela 2006; Williams 1995) – highlighting the problems with relying on the "counselling" portion of VCT to encourage HIV preventative behaviour – prevention of HIV transmission was still seen by the participants to result from an HIV test. Rather than increasing an individual's "knowledge" or "awareness" of HIV, however, testing was seen to lead to HIV prevention because using condoms was one part of living a healthy life. The commitment to "healthy living" behaviour changes (which encompassed eating a nutritious diet, exercising, surrounding ones' self with supportive people, thinking positively, and talking openly about HIV, in addition to condom usage and sexual behaviour change) was seen to result from "knowing where you stand in life" after receiving an HIV test result. In fact, HIV testing and knowing one's status were, themselves, perceived as a part of living healthily and caring about one's self. Thus, in addition to being a product of the HIV test, participants were actively encouraged to test because they felt it could initiate a healthy future. If these messages of "positive living" continue to be linked with HIV testing (regardless of the test result) and the elements of healthy living include social and psychological factors (and not simply sexual behaviour change), it is possible that testing uptake will increase.

In addition to prevention, participants were aware that HIV testing was a gateway to receiving antiretroviral treatment. Seen as the primary method for mitigating the physical threat of being infected with HIV, provision of ARV treatment was not only a crucial benefit of but also as a motivation for VCT. Furthermore, aware that the effectiveness of ARVs was dependent on the stage of HIV infection during which they were initiated, participants stressed the importance of testing early and regularly for HIV. Recognition by the study participants that HIV testing could lead to treatment interventions illuminates the potential barrier to testing that is created through a lack of

access to treatment, as discussed in the literature. The frequency with which participants included the topic of HAART in discussions of the benefits of voluntarily testing for HIV suggests that availability and access to ARVs are important for encouraging HIV testing and that lack of access may indeed be a barrier to the uptake of VCT. However, as supported in the literature, it was clear from discussions of the social and psychological threats that one was exposed to through HIV testing that the provision of antiretroviral treatment did not simply function as a mitigation of the physical threat and therefore cannot always be seen to encourage the uptake of testing (Gilmore and Somerville 1994; Kalichman and Simbayi 2003). Attending public health care facilities and standing in designated "ARV treatment" queues at the clinic transformed ARVs as a mitigation of the physical threat into a means of exposing an individual to the social threats also attached to living with HIV. It is for this reason that tasking HIV positive clients with the responsibility of adhering to ARV treatment in the absence of efforts to reduce the social and psychological threats associated with being positive amounts to "unsound public health practice" (Tarantola 2005) and will ultimately be unsuccessful (Robins 2006). Furthermore, it highlights how important the inclusion of personal experiences is into the understandings of people's choices and motivations around managing their own health.

Contrary to literature suggesting that there is a lack of awareness regarding HIV/AIDS and the importance of HIV testing, the nuanced understanding of HIV prevention and the dual function of ARVs to both mitigate physical threats and expose one to social and psychological threats demonstrate that participants, in fact, had *multiple* kinds of knowledge. Participants had detailed and comprehensive knowledge of the physical threats and the clinical implications of HIV infection. The treatment and prevention goals following an HIV test that are salient to researchers, academics, and health care practitioners were relevant to the participants. High levels of knowledge were also evident in the participants' description of opportunistic infections, their knowledge of how to take ARVs and why they worked, and the important role that early and regular testing had on disease prognosis. To compliment this form of knowledge, participants also revealed a great deal of knowledge regarding the perceived negative social and psychological consequences of being infected with HIV. They witnessed or had heard about the social isolation that sometimes followed an HIV positive diagnosis. Siblings or relatives had been "dumped" by their partners after revealing their HIV status. They experienced the depression or mental break down of family members who could not cope with the psychological stresses of living with HIV. One participant described how his uncle "ended up dead" because he did not accept his own status and another described how her sister's life was "just miserable" because she could not come to terms will her illness. They observed the frailty and helplessness of people suffering from opportunistic infections. The image of a "small

baby" surfaced repeatedly and was used to describe aunts, teenagers, and friends. This caused the participants to feel an acute sense of vulnerability attached to HIV infection and they acknowledged the shame associated with not being able to care for one's self or having to rely on others for life support.

This unique sampling group does not allow for an exploration of the link between lack of knowledge and low levels of testing (because all but 1 had tested and knowledge was comprehensive) but it can help to critique the link between increased biological or clinical knowledge and increased levels of testing. The participants' decisions to test for HIV, as will be articulated in Chapter 5 through case studies, were not a response to high levels of knowledge regarding AIDS or ARV treatment but rather a decision based on their cumulative experience of the perceived physical, social, and psychological consequences of living with HIV. Certain types of knowledge can be seen to encourage uptake of HIV testing, while others can discourage VCT. Thus, rather than a lack of knowledge, low levels of testing may be due to conflicting types of knowledge.

Participants did not discuss access to VCT services as a barrier to HIV testing. Furthermore, since all but one had tested (and her reasons for not testing did not relate to issues of access), this study cannot support "limited access to VCT" as a useful explanation for the causes of such low testing rates. It is clear, however, that individuals must have the ability to test for HIV so that when they become biased towards testing they can carry out this action.

Chapter 5 – Testing: The balance between physical, social, and psychological threats

5.1 Introduction

The interplay between the physical, social, and psychological threats and whether they were managed or catalysed by testing can be used to understand HIV testing behaviour. The decision to test can be conceptualised as a balance between perceived physical threats, which encourage testing, and perceived social and psychological threats, which discourage testing.

As was clearly evident, the physical threats of HIV/AIDS (such as opportunistic infections and death) were managed through healthy living and the commencement of ARVs, both of which were initiated only after an HIV test. Conversely, the act of testing very often exposed HIV positive individuals to the social and psychological threats associated with AIDS, created through the public or private acknowledgement that one was infected. Rather than looking at each of these threats in isolation, it is likely that an individual will consider all three when making a decision about getting tested for HIV. An individual's perception of the likelihood and severity of each of these three threats in their own lives determines whether or not they will be biased towards testing. Thus, testing behaviour can be conceptualised as a balancing act, a weighing of risks and benefits, between the physical, social, and psychological threats that are present when one is living with HIV.

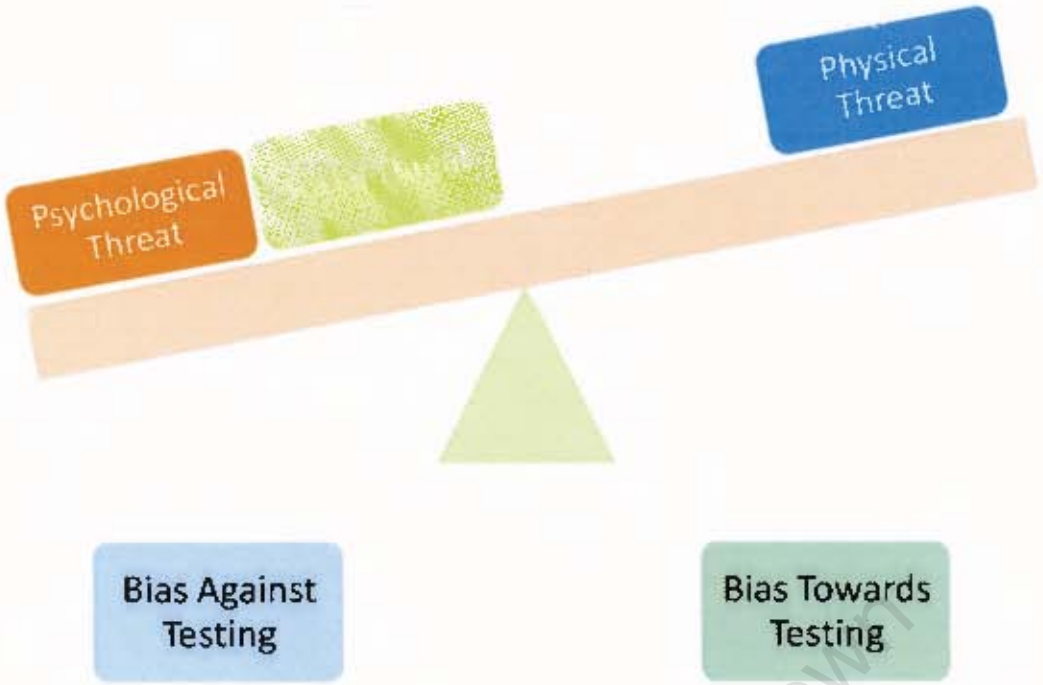
This chapter will propose a model for understanding the interplay between physical, social, and psychological threats. The threat-balance model will compliment and expand upon the empirical data from Chapter 4 by showing how the perceived threats of living with HIV exist in different degrees for each individual. Through case studies of the participants, a tipping point (the point at which each participant moved from an individual bias against testing to an individual bias towards testing) will be identified. This will show that it is an individual's balance of the three perceived threats that will amount to an individual bias towards testing.

5.2 Threat-Balance Model

To understand this balancing act, and most importantly the point at which an individual decides to voluntarily test for HIV, a conceptual model will be used to explain the relationship between physical, social, and psychological threats. Using the visual image of a balance, the model shows

how the differing weights of each threat tip the balance in one direction or the other, either biasing an individual towards testing or against testing for HIV.

To echo the empirical data collected in this study, this model places social and psychological threats on one side of the balance and physical threats on the other. This is because social and psychological threats have a similar effect on testing behaviour, and both have a contradictory effect to physical threats. When the balance is tipped to the social and psychological threats, signifying that the damage due to social and psychological threats is perceived as greater than the damage due to the physical threats, an individual will be biased against HIV testing (to the left of the above model). When the model is tipped towards the physical threats on the right, suggesting that the individual perceives the damage due to physical threats to outweigh the perceived social and psychological threats, an individual will be biased towards testing for HIV (to the right in the above model). The model below shows an individual bias against testing.



The tipping point, or the point at which the balance tips from left to right, is when an individual becomes biased towards testing, and if provided with an opportunity, will test for HIV.

There are two main ways that the balance may tip from left to right, biasing an individual towards HIV testing: 1.) the physical threats posed by HIV increase or become so strong that mitigating the physical damage through HIV testing is seen as more desirable than preventing the perceived social and psychological threats; or 2.) the likelihood or severity of the social and psychological threats is reduced, thereby making the physical threats heavier in comparison and tipping the balance towards a testing bias.

Understanding the interplay between physical, social, and psychological threats requires two related processes. The first process focuses on an individual's perception of each threat. Individuals will vary in their perception of the likelihood and severity of the physical, social, and psychological threats, as well as the impact that an HIV test will have on either mitigating or exposing them to damage. The variations in perception of the threats, when viewed in relation to one another, serve to explain the position of the balance, either biased towards or against testing. The second process observes the point at which the balanced shifts from a bias against testing to a bias towards testing, caused by a change in perception of one or all of the threats, understood here as the "tipping point." Thus it is the *change* in perception of threats over time that fuels the tipping point.

To illustrate the variation in perception of the three threats of being HIV positive, as well as the point at which an individual becomes biased towards testing, participants' individuals testing stories will be examined in the form of case studies. As space restrictions do not permit the retelling of all 15 stories, two case studies will be presented. Each story demonstrates the change in perception of a different threat, but the effect of "tipping" the participant to an individual bias towards testing is consistent.

Case Study 1: Xola

Xola is a 20-year-old female from Nyanga East. She was born in Cape Town and has lived in Nyanga all her life. She lives with her mother, her uncle, her sister, and her cousin. Her mother's sister and two children sometimes come to visit Xola and her family in Nyanga.

Two of the five people in Xola's house are HIV positive. She also has an aunt who is infected and an uncle who had recently died due to AIDS. Considering this experience, she describes her feelings about HIV/AIDS.

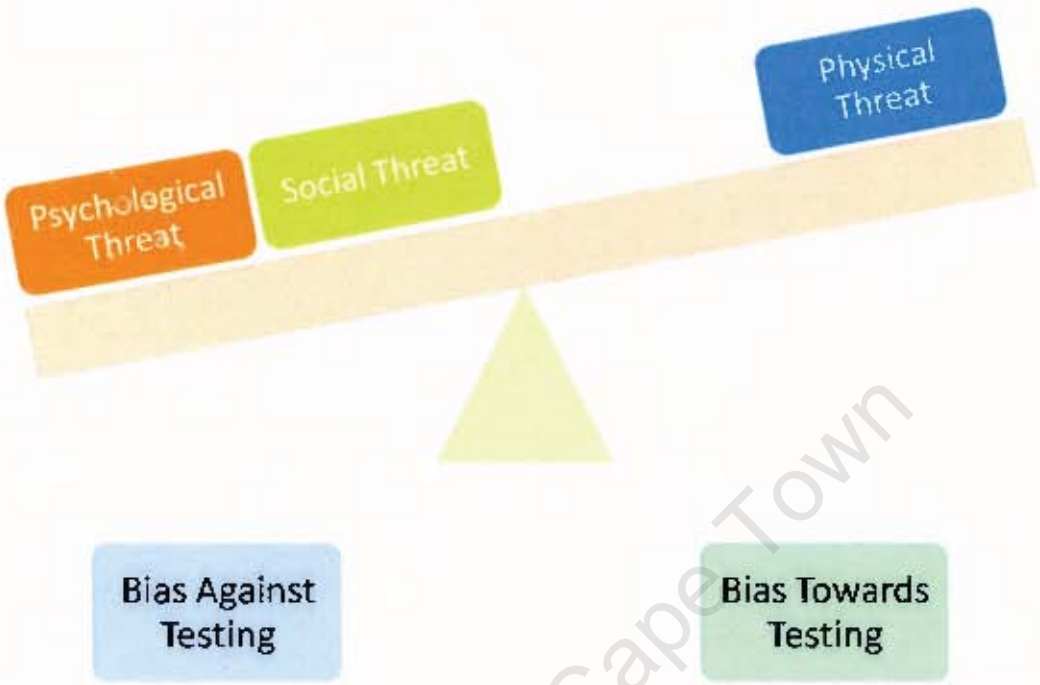
> *Like for me I don't judge anyone who is HIV positive because I have had an uncle who died in January with HIV/AIDS and I could not, I did not insult him at home...There was some people who did not want to accept [him]. And now I'm living with two people at home who are HIV positive of which, like, it's like they are still like the same person as you are it's just that they have the virus...nothing changed with them.*

In addition to having an intimate experience with AIDS in her home and with her family, Xola was optimistic about the outcome for those who were living with AIDS. She believed that with personal acceptance of status, healthy living, and ARVs, an HIV positive person could survive a long time and sometimes even outlive an HIV negative person. Part of Xola's acceptance of HIV/AIDS and her strong belief in HIV testing may have resulted from her uncle's death. Xola described what her uncle told her before he died.

> *And, like, my uncle before he died he said to us, he told us not to be ashamed of him and we must tell everyone why, what causes, what caused his death. We must explain what HIV is and talk and that he died of HIV and that he is not ashamed of it himself so that he can die happier and willingly.*

Xola's perception of the social and psychological threats that one was exposed to by being HIV positive were considerably low. She had an accepting family that openly discussed HIV/AIDS-related topics. She believed that HIV positive people no different than HIV negative people. Her knowledge of the physical threats presented by HIV, and subsequent benefits of testing, were also high.

However, it is clear from Xola's testing story that her perception of the physical threats was not strong enough initially to outweigh the social and psychological threats also associated with having HIV. The threat-balance model representing her initial state can be represented like this:



She describes the moment when this changed for her.

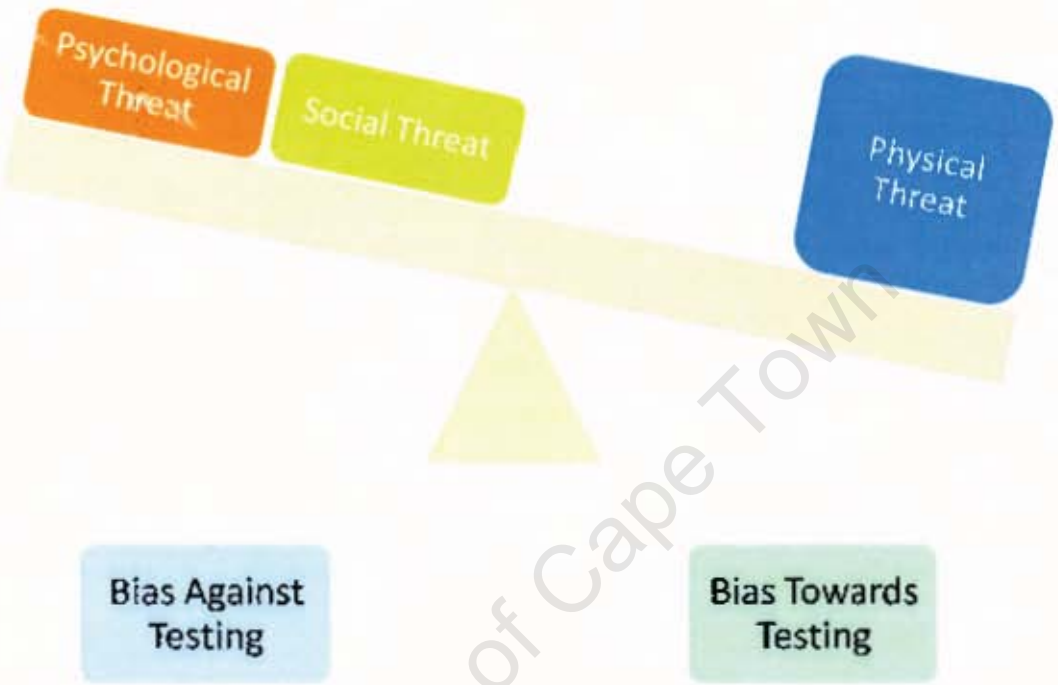
> *The reason why I choose to go get tested...when I found out that my uncle was HIV positive there was nothing great for me to go get tested. But when my sister, my mother's sister told me that she was HIV positive and like her kids were HIV negative then I thought like if like the kids were also HIV positive, what would [that] put me in? That is, what is my, what would my status be? Then from that day when she told me, explained to me that she is HIV positive and she is happy that her kids are not HIV positive, like, I decided to go get tested so that like I had to know my status.*

Although she was aware of the physical threats of being HIV positive and she had a low perceived social and psychological threats because of the strength and acceptance of her family, it was not until she felt a personal likelihood of infection that she decided to go and get tested for HIV. The likelihood of infection increased for Xola when she considered the possibility that someone her age could also be infected with HIV. This highlights that Xola perceived generational differences for the physical threat of HIV infection. In her reactions to the negative test result, it is clear that Xola perceived a very strong physical threat for herself at the time she decided to test.

> *I was very scared, I was very scared...I thought, like, what if I'm HIV positive? Like already, let's say half of my family is HIV positive and there is a possibility that I might be HIV positive*

too. I was very scared really. I won't lie. Even when the counsellor told me my results I was very shocked, I was very shocked.

Xola's tipping point from an individual bias against testing to an individual bias towards testing resulted from the heightened likelihood of the physical threat posed by HIV infection. The model below represents the change in her perception of the physical threat:



This is the point when Xola chose to get tested.

Case Study 2: Bulelani

Bulelani is a 25-year old male who grew up just outside of Umtata in the Eastern Cape. He defines his hometown as a "rural area." Bulelani moved to Guguletu, Cape Town a year ago and lives now with his brother. He has a few sisters who also live in Cape Town but the majority of his very large extended family still lives in the Eastern Cape. He goes back often to visit them. His girlfriend still lives in the Eastern Cape.

Many of the members of Bulelani's family are nurses. At least four of his sisters or aunts are nurses, which he stated while explaining that he had learned about HIV/AIDS at home. Bulelani has also had family members who were infected with HIV. In particular, Bulelani spoke of two uncles who had contrasting stories of HIV infection. He described why he believed one of his uncles died.

I had an uncle who had AIDS. But he died. Yeah. And I spoke to him how easy is, you know, and my uncle he didn't want to accept that he had AIDS. He ended up using alcohol, smoke cigarettes, and used to smoke dakka. Also he didn't want to eat his treatment. And he ended up dead.

Despite claiming that he did not know very much about HIV/AIDS before moving to Cape Town because he grew up in a rural area that had limited access to information, Bulelani was aware of the methods of HIV prevention and believed in the possibility for survival through using ARVs and practicing healthy living. These healthy behaviours included using condoms during sex, going to the clinic or to get counseling, talking about it, and accepting it. He was optimistic that HIV infection did not signify death. From witnessing one uncle die of AIDS, he was aware of the opportunistic infections that were associated with the advanced stages of HIV.

Bulelani's experience of getting tested highlights a different shift in perception from the tipping point observed in Xola's story above. He first explains that he did not personally choose to get tested for HIV, but rather was forced to go to the clinic by his girlfriend.

Bulelani: Firstly, I didn't want to. But I've got a girlfriend. So he (sic) forced me to go test with her. So that is why I went. But I didn't want to.

Hannah: What did she say to force you to come?

Bulelani: She said if I really love her I should go with her to get tested. So I thought about that...[In the waiting room of the clinic] I thought to change my mind. To not get tested. Yeah. But for the sake of my girlfriend...

When he reflected on why he did not want to get tested, he cited fear of acknowledgement of status, driven, in part, because he did not know whether or not he was infected with HIV. He had also explained during his interview that he regularly cheated on his girlfriend and did not always use condoms. In an illustration of the perception that internal shame resulted from being diagnosed with HIV after knowingly engaging in unprotected sexual behaviour, Bulelani talked about his fear of acknowledging he could be HIV positive.

I was afraid. I was afraid of getting tested because I didn't know that I had or [HIV or not]. I didn't know about my status.

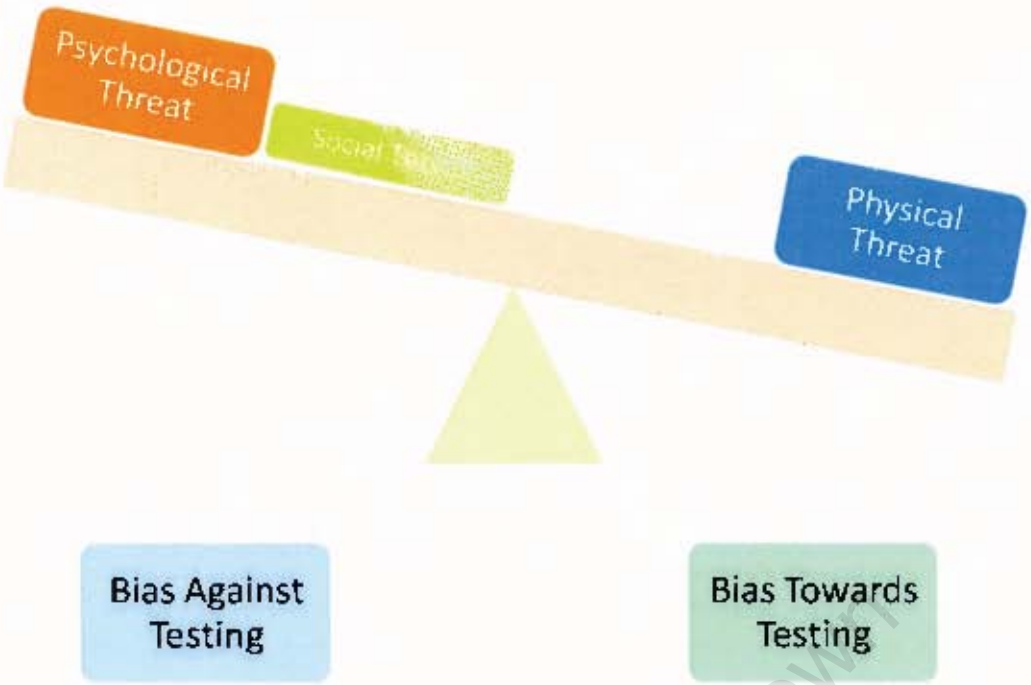
From Bulelani's story, it appears that his perception of the physical threat was strong, given his experience of a dying uncle and the knowledge he gained from the nurses in his family. It also appears that Bulelani perceived a strong psychological threat to being diagnosed with HIV. Although

he also perceived a physical threat associated with living with HIV, it was not strong enough to bias him towards testing for HIV. Here is a model representing Bulelani's perception of the threats before he tested for HIV:

Only through his explanation of what allowed him to go through with the HIV test does his tipping point become clear. In the waiting of the clinic, Bulelani describes what happened just before he tested.

> *[My girlfriend] was close to me. She sat next to me. Wow. And put [her arms around] my body. She hug me...Also, [she said] it doesn't matter if we have AIDS 'cause she will always be there for us.*

Unconditional love and support from his girlfriend, regardless of the outcome of his HIV test, reduced Bulelani's perception of the social threats of living with HIV. The lifting of perceived social threats, while his perceptions of the psychological and physical threats of HIV remained the same, was enough to shift Bulelani's threat-balance in the direction of a bias towards HIV testing. The model below represents Bulelani's change in perception of the three threats at the time he chose to test for HIV.



As is evident from both models, a reduction in the social threat of being HIV positive enabled Bulelani to voluntarily test for HIV.

5.4 Discussion

All 15 of the participants' stories of voluntarily testing for HIV demonstrate a different balance of the perceived threats of living with HIV. The model functions in a similar way across all cases (in that the physical threats must outweigh the social and psychological threats in order to have an individual bias towards testing), but the weight of each perceived threat (represented in the model by the size of the blocks) can only be compared within in an individual's testing story and must be looked at over time. It is the difference in perception of one or all of the threats, compared before and after an individual is disposed to testing (and in this case, has tested), that illustrates the tipping point of the model.

Returning to the literature regarding disease and illness and the biopsychosocial model of health, this threat-balance model clearly demonstrates how three aspects of HIV/AIDS – physical, social, and psychological threats – function simultaneously and in conjunction to influence an individual's health seeking behaviour. Just as the biopsychosocial model was developed to account for both patient and practitioner understandings of ill-health (Engel 1977), and more specifically both the clinical diagnosis of disease and the social experience of the illness (Kleinman 1980), the threat-balance model looks at multiple meanings of AIDS and HIV in an effort to better account for HIV testing

behaviours. Whereas the biomedical model "views the body as a machine and the disease as a damage to it, the doctors' function being to repair the injuries caused" (Nascimento-Schulze, Garcia, and Arruda 1995:2), the threat-balance model unites the mind and body and presents individuals as beings who have complex understandings of their own health and knowledge about how to achieve a holistic well-being. Thus, rather than further divide doctor and patient understandings of health (where practitioners focus on physical symptoms and patients are concerned with social and psychological experiences), the threat-balance model shows that individuals use multiple paradigms of health, *including* biomedical understandings, to create a fuller approach to health.

This model is significant because it demonstrates that interventions targeted at only one part of this model, such as expanded ARV treatment that promises to mitigate the physical threat, do not consider the weight of other threats that also influence an individual's decision to test. Similarly, efforts to increase confidentiality within testing services must also understand the social threat presented by the relationship between nurse and patient or the psychological threat to which one is exposed merely through learning of one's HIV status, neither of which is reduced through increased confidentiality.

The concept of a "tipping point" was popularised by Malcolm Gladwell (2002) in his book *The Tipping Point: How Little Things Can Make a Big Difference*. This book addressed the phenomenon behind an epidemic[16] – whether the epidemic was the emergence of fashion trends, changes in the incidence of crime, the sudden popularity of a book or activity, or the drastic rise and fall of sexually transmitted infections. In understanding these phenomena, Gladwell identified three characteristics that define epidemics: "one, contagiousness; two, the fact that little causes can have big effects; and three, that change happens not gradually but at one dramatic moment" (Gladwell 2000:9). From these characteristics of an epidemic, he formed the concept of the tipping point.

> The third trait – the idea that epidemics can rise and fall in one dramatic moment – is the most important, because it is the principle that makes sense of the first two and that permits the greatest insight into why modern change happens the way it does. The name given to that one dramatic moment in an epidemic when everything can change all at once is the Tipping Point (Gladwell 2000:9).

The application of a tipping point used in this thesis to understand HIV testing departs slightly from Gladwell's definition in two significant regards. Firstly, while Gladwell's tipping point describes the

[16] Gladwell did not limit his definition of an epidemic simply to diseases that originate as biological pathogens. Rather, he believed that "ideas and products and messages and behaviors spread just like viruses do" and therefore they were best thought of as epidemics (Gladwell 2000:7).

ebbs and flows within a population, the tipping point in this thesis illustrates the changes within an individual. Gladwell sought to understand how mass action takes shape, how it is initiated, and what drives large-scale widespread change, not how individuals make decisions. This is an important distinction because Gladwell's tipping point shows how people influence each other to create mass change. The second departure from Gladwell's tipping point is that the model used in thesis shows a balance of opposing forces: physical threats balanced against social and psychological threats. The HIV testing tipping point is explained through the *relationship* between these threats, and not simply the isolated change of one of them.

However, the three characteristics of epidemics described by Gladwell are useful for understanding some elements of the tipping point of HIV testing practices. Firstly, little causes can have significant consequences. There are many factors that influence the decision to test for HIV – presented above as physical, social, and psychological threats – and it may take a small change in only one threat to tip the balance in favour of HIV testing. In fact, each of the three threats is made up of lots of little parts (physical threats include death, opportunistic infections, helplessness, each of which can be broken down into many different personal experiences) and change in only one part of one threat may shift the balance, change the relationship between the perceived threats, and create a big effect – the decision to test for HIV. Secondly, change is not gradual but dramatic. The change from a bias against testing to a bias towards testing happens with one tip of the balance. There is no middle ground between testing and not testing. In many of the testing stories presented by the participants in this study, there was a moment when they decided to test, and this was informed by the dramatic change in one of their perceived threats. While it is necessary to stress that decisions to test are the result of an individual's cumulative experience of HIV/AIDS, and thus comprised of many pieces of information acquired over time, there may be a moment when a small change in perception has a big impact on the decision to test for HIV.

Lastly, Gladwell states that epidemics are contagious. While less applicable to individual decisions regarding HIV testing, this concept may help to explain the potential of HIV testing campaigns. One spark, one small change in the trends of HIV testing may lead to a landslide effect of increased demand for HIV testing within the South African population. From the findings of this study, it is clear that more attention needs to be spent on reducing the perceived social and psychological threats attached to living with HIV. It is likely that with a reduction of these threats, in partnership with increased opportunities for the mitigation of physical threats through HIV testing, the demand for voluntary HIV testing will greatly increase (Tarantolla 2005). In the same way that stigma and discrimination towards AIDS spread within a population, so too can the reduction of stigma, the

trends towards HIV testing, and the actualisation of the prevention and treatment initiatives that are ultimately desired. After all, "AIDS is fundamentally a social phenomenon. It spreads because of the beliefs and social structures and poverty and prejudices and personalities of a community...we might [halt] the spread of AIDS far more effectively just by focusing on those beliefs and social structures and poverty and prejudices and personalities" (Gladwell 2000:261-2).

Chapter 6 – Conclusion and Recommendations

This thesis has explored HIV testing behaviour among a group of young adults from Cape Town, South Africa. The participants interviewed for this research comprised a unique study sample, with 14 of the 15 (93%) participants having tested for HIV in a country where the population average for those who have been tested is roughly 30% (Shisana et al. 2005) and even lower for their age group. By interviewing young South Africans who had chosen to voluntarily test for HIV, this study has been able to explore participants' understandings and experiences of HIV/AIDS in their daily lives both before and after they had tested for HIV and is thus able to demonstrate the relevant factors that contributed to their uptake of VCT.

Originally an investigation into the links between the ARV rollout and uptake of VCT services, this study found that a number of factors (not limited to ARV treatment) were considered by participants before testing for HIV. As shown, participants identified a number of threats that they perceived to be associated with HIV infection. Their decisions of whether or not to test can be explained by observing how an HIV test impacted upon each of these threats. Participants identified physical threats presented by HIV infection. They perceived death to be closely linked with AIDS and all but one participant had experienced a family member or close friend die of AIDS. Many participants also listed opportunistic infections in their description of HIV infection. These, too, had often been experienced by people close to the participants. Two participants were HIV positive and one had experienced AIDS-related sicknesses. Participants also identified social and psychological threats that one was exposed to when living with HIV. Social isolation, rejection, and blame were perceived by participants to follow an HIV positive diagnosis. Many of them told stories of people they knew who had been dumped by partners after revealing an HIV positive status. They were also acutely aware of the gossip that circulated around their communities. Although many disputed the rumours that were spread about HIV positive people, gossip was viewed as a negative and damaging consequence of living with HIV. In addition to these social threats, participants identified mental destruction, lack of personal acceptance, and shame to be psychological threats that a person was exposed to when living with HIV. They often attributed the death of family members from AIDS, in part, to the stress and depression that accompanied personal awareness of an HIV positive status. Psychological threats were personally significant to some participants even though they had not tested positive for HIV because they were aware that it was difficult to predict how one would react to a test result. For this reason, it was the possibility of mental destruction, thoughts of suicide, and loneliness that guided their decisions around testing.

Observation of the impact that testing had on either mitigating or exposing one to these threats adds depth to experience of HIV testing. Participants had a strong sense that VCT was a way of reducing the physical threats associated with HIV infection. They were well versed in the details of ARV treatment and gave powerful stories of the possibility of survival and optimism in spite of HIV infection. Testing was a crucial factor in each participant's mind for mitigating physical threats. Conversely, testing had the potential of initiating the social and psychological threats they associated with living with HIV. When these threats were strongly felt, testing was no longer viewed only as a way of mitigating potential dangers of HIV infection but rather came as an unwanted pathway to undesirable outcomes. Especially in circumstances were an HIV positive person was not physically ill with opportunistic infections, HIV testing was seen to create more dangers than it mitigated.

The model presented in Chapter 5 to illustrate the three threats identified by participants and the impact that an HIV test had on either mitigating or exposing an HIV positive person to these threats demonstrates how individuals view health and illness. Unlike biomedical models of health that function to separate the physical body from the social and psychological experience of illness, the threat-balance model incorporates both disease and illness-oriented factors when understanding health-seeking behaviour. This model was born out of the experiences and stories of the participants in this study.

This thesis recommends that in order to increase the rates of voluntary testing and counselling and the subsequent opportunities for HIV prevention and provision of ARV treatment, all three perceived threats posed on HIV positive people must be addressed. While continued reduction of the physical threat through HIV testing (ARV treatment, healthy living, condom usage, etc) must be emphasized, this study has shown that similar attention should be spent on reducing the social and psychological threats that one is also exposed to when living with HIV.

Importantly, this model helps to highlight a missing link in the debate between VCT and PITC as a means to increase rates of HIV testing (Cameron 2005; De Cock 2003; Heywood 2005), and that is whether testing itself is the marker of future prevention, care, and survival. Statistically, "if the end goal of [routine testing] is to test a larger proportion of the population, it has succeeded" (Kenyon 2005:22). However, it is not the test *per se* that allows for prevention and treatment interventions to happen, but the environment for the individual after a positive test result. Thus, regardless of how testing is conducted, it is actually the threats that a person who *is* tested faces following the test result that determine the true value of an awareness of status. It is the threats associated with being HIV positive, and not merely the methods of testing that are a barrier to HIV testing.

Bibliography

Abadía-Barrero, César Ernesto and Arachu Castro. 2006. Experiences of stigma and access to HAART in children and adolescents living with HIV/AIDS in Brazil. *Social Science & Medicine.* 62:1219-1228.

Abdool Karim, Quarraisha. 2005. Heterosexual transmission of HIV - the importance of a gendered perspective in HIV prevention. In *HIV/AIDS in South Africa*, edited by S.S. Abdool Karim and Q. Abdool Karim. pp.243-261. Cambridge: Cambridge University Press.

Almeleh, Colin. 2006. Why Do People Disclose Their HIV Status? Qualitative Evidence from a Group of Activist Women in Khayelitsha. In *Centre for Social Science Research Working Paper 163*. Cape Town: Centre for Social Science Research, University of Cape Town.

Ajzen, Icek. 1988. *Attitudes, personality and behavior.* Chicago: Dorsey Press.

Asante, AD. 2007. Scaling up HIV prevention: why routine or mandatory testing is not feasible for sub-Saharan Africa. *Bulletin of the World Health Organization.* 85(8):644-646.

Ashforth, Adam, and Nicoli Nattrass. 2005. Ambiguities of 'Culture' and the Antiretroviral Rollout in South Africa. *Social Dynamics*. 31(2):285-303.

Barnowski, Tom, Karen W. Cullen, Theresa Nicklas, Deborah Thompson, and Janice Barnowski. 2003. Are Current Health Behavioral Change Models Helpful in Guiding Prevention of Weight Gain Efforts. *Obesity.* 11(10):23S-43S.

Bandura, Albert. 1977. *Social Learning Theory.* Englewood Cliffs, NJ: Prentice-Hall, Inc.

Bandura, Albert. 1997. *Self-efficacy: The Exercise of Control.* New York: W.H. Freeman and Company.

Bayer, Ronald, and Amy Fairchild. 2006. Changing the Paradigm for HIV Testing - The End of Exceptionalism. *New England Journal of Medicine.* 355(7):647-649.

Bernard, H. Russell. 2006. *Research Methods in Anthropology: Quantitative and Qualitative Approaches.* Lanhan, MD: Altamira Press, Rowman & Littlefield Publishers, Inc.

Bourdieu, Pierre. 1984. *Distinction: A Social Critique of the Judgement of Taste.* London: Routledge & Kegan Paul plc.

Bourdieu, Pierre. 1985. The Social Space and the Genesis of Groups. *Theory and Society.* 14:723-744.

Bourdieu, Pierre. 1986. *Outline of a Theory of Practice.* Cambridge: Cambridge University Press.

Bourdieu, Pierre. 1990. *The logic of practice.* Cambridge, UK: Polity Press.

Butler, Anthony. 2005. South Africa's HIV/AIDS Policy, 1994-2004: How Can It Be Explained? *African Affairs.* 104(417): 591-614.

Calhoun, Craig. 1993. Habitus, Field, and Capital: The Question of Historical Specificity. In *Bourdieu: Critical Perspectives*, by Craig Calhoun, Edward LiPuma and Moishe Postone. pp.61-88. Cambridge: Polity Press.

Cameron, Edwin. 2005. *Witness to AIDS.* Cape Town: Tafelberg Publishers

Campbell, Catherine. 2003. *'Letting Them Die': Why HIV/AIDS Intervention Programmes Fail.* Oxford: The International African Institute in association with James Currey.

Chopra, Mickey, Carl Kendall, Zelee Hill, Nikki Schaay, Lungiswa L. Nkonki, and Tanya M. Doherty. 2006. 'Nothing New': responses to the introduction of antiretroviral drugs in South Africa. *AIDS.* 20:1975-1977.

City of Cape Town. 2003-2008. Strategic Development Information and GIS. Available at: http://www.capetown.gov.za/wcmstemplates/sdigis.aspx?clusid=477&IDPathString=6952&catparent=6952 (Accessed 1 February 2008).

Cullinan, Kerry. 2003. Govt. runs out in prime time. *health-e.* June 24, 2003. Available at: www.health-e.org.za (Accessed 28 January 2008).

Daftary, A., N. Padayatchi, and M. Padilla. 2007. HIV testing and disclosure: a qualitative analysis of TB patients in South Africa. *AIDS Care.* 19(4):572-577.

Day, J. H., K. Miyamura, A. D. Grant, et al. 2003. Attitudes to HIV voluntary counselling and testing among mineworkers in South Africa: will availability of antiretroviral therapy encourage testing? *AIDS Care.* 15(5):655-672.

De Cock, Kevin M. 2005. HIV Testing in the Era of Treatment Scale Up. *Health and Human Rights.* 8(2):31-35.

De Cock, Kevin M., Dorothy Mbori-Ngacha, and Elizabeth Marum. 2002. Shadow on the continent: public health and HIV/AIDS in Africa in the 21st century. *The Lancet.* 360:67-72.

Department of Health. 2002a. *Revised National Curriculum Statement Grades R-9 (Schools): Life Orientation.* Pretoria: Department of Health.

Department of Health. 2002b. *VCT Sites List.* Available at: http://www.doh.gov.za/aids/docs/vct-sites.html (Accessed 31 March 2008).

Department of Health. 2003. Khomanani Addresses Key Communications Issues of HIV and AIDS. *South African Government Information.* April 14, 2003. Available at: http://www.info.gov.za/speeches/2003/03041514011002.htm (Accessed 28 January 2008).

Department of Health. 2005. *National VCT List for 2005.* Available at: http://www.doh.gov.za/aids/docs/nsl.html (Accessed 31 March 2008).

Department of Health. 2007. Re-launch of the Khomanani Campaign. *South African Government Information.* May 9, 2007. Available at: http://www.info.gov.za/speeches/2007/07050915451001.htm (Accessed 28 January 2008).

Dorrington, Rob, Leigh Johnson, Debby Bradshaw, and Timothy-John Daniel. 2006. *The Demographic Impact of HIV/AIDS in South Africa: National Prevalence Indicators for 2006.* Cape Town: Centre for Actuarial Research, South African Medical Research Council, and Actuarial Society of South Africa.

Eaton, L., Alan J. Flisher, and Leif E. Aarø. 2003. Unsafe sexual behaviour in South African youth." *Social Science & Medicine.* 56:149-165.

Engel, George L. 1977. The Need for a New Medical Model: A Change for Biomedicine. *Science.* 196(4286):129-136.

Farmer, Paul. 1996. Women, Poverty, and AIDS. In *Women, Poverty, and AIDS: Sex, Drugs, and Structural Violence*, by Paul Farmer, Margaret Connors and Simmons Janie. pp.3-38. Monroe, Maine: Common Courage Press.

Farmer, Paul. 2001. *Infections and Inequalities: The Modern Plagues*. Berkley: University of California Press.

Farmer, Paul. 2003. *Pathologies of Power: Health, Human Rights, and the New War on the Poor.* Berkley: University of California Press.

Fishbein, Martin, and Icek Ajzen. 1975. *Belief, attitude, intention, and behavior: an introduction to theory and research.* Reading, MA: Addison-Wesley.

Flykesnes, Knut, and Seter Siziya. 2004. A randomized trial on acceptability of voluntary HIV counselling and testing. *Tropical Medicine and International Health.* 9(5):566-572.

Galvão, Jane. 2002. Access to antiretrovirals in Brazil. *The Lancet.* 360:1862-1865.

Gebrekristos, Hirut T., Mark N. Lurie, Nkosinathi Mthethwa, and Quarraisha Abdool Karim. 2005. Knowledge and acceptability of HAART among TB patients in Durban, South Africa. *AIDS Care.* 17(6):767-772.

Geffen, Nathan, Nicoli Nattrass, and Chris Raubenheimer. 2003. The Cost of HIV Prevention and Treatment Interventions in South Africa. In *Centre for Social Science Research Working Paper 28.* Cape Town: Centre for Social Science Research, University of Cape Town.

Gilmore, Norbert and Margaret A. Somerville. 1994. Stigmatization, scapegoating and discrimination in sexually transmitted diseases: overcoming "them" and "us." *Social Science & Medicine.* 39(9):1339-1358.

Gladwell, Malcolm. 2000. *The Tipping Point: How Little Things Can Make a Big Difference.* New York: Little Brown and Company.

Glaser, Barney G., and Anslem L. Strauss. 1967. *The Discovery of Grounded Theory: Strategies for Qualitative Research.* Chicago: Aldine.

Glick, Robert. 2005. Scaling Up HIV Voluntary Counseling and Testing in Africa: What Can Evaluations Tell Us About Potential Prevention Efforts? *Evaluation Review.* 29(4):331-357.

Goffman, E. 1963. *Stigma: Notes on management of spoiled identity.* Englewood Cliffs: Prentice Hall.

Google Maps. 2008. *Welcome to Google Maps.* Available at: http://maps.google.com/ (Accessed on 2 April 2008).

Hahn, Steven R. 2001. The Physician-Patient Relationship: Physical Symptoms and Physician Experience Difficulty in the Physician-Patient Relationship. *Annals of Internal Medicine.* 134(9):897-904.

Harrison, Abigail. 2005. Young people and HIV/AIDS in South Africa: Prevalence of infection, risk factors and social context. In *HIV/AIDS in South Africa*, edited by S.S. Abdool Karim and Q. Abdool Karim. pp.262-284. Cambridge: Cambridge University Press.

Healthlink Worldwide. 2006. Treatment literacy: empowering communities to access AIDS treatment. *Healthlink Worldwide, Findings 6*. Available at: www.healthlink.org.uk (Accessed December 2006).

Helman, Cecil G. 1981. Disease versus illness in general practice. *Journal of the Royal College of General Practitioners.* 31:548-552.

Helman, Cecil G. 2000. *Culture, Health and Illness.* Oxford: Butterworth-Heinemann.

Heywood, Mark. 2004. The Price of Denial. *Development Update* 5(3):93-122.

Heywood, Mark. 2005. The Routine Offer of HIV Counseling and Testing: A Human Right. *Health and Human Rights.* 8(2):13-19.

Hutchinson, P.L. and X. Mahlalela. 2006. Utilization of voluntary counseling and testing services in the Eastern Cape, South Africa. *AIDS Care.* 18(5):446-455.

Hutchinson, P.L., X. Mahlalela, and Josj Yukich. 2007. Mass Media, Stigma, and Disclosure of HIV Test Results: Multilevel Analysis in the Eastern Cape, South Africa. *AIDS Education and Prevention.* 19(6):489-510.

Iliffe, John. 2006. *The African AIDS Epidemic: A History.* Athens: Ohio University Press.

Joffe, Helene. 1995. Social Representations of AIDS: Towards Encompassing Issues of Power. *Papers of Social Representations.* 4(1):1-40.

Joffe, Helene. 2003. Risk: From Perception to Social Representation. *British Journal of Social Psychology.* 42:55-73.

Jones, Edward E., and Harold B. Gerard. 1967. *Foundations of Social Psychology.* New York: John Wiley & Sons, Inc.

Kalichman, S.C. and Simbayi, L.C. 2003. HIV testing attitudes, AIDS stigma, and voluntary counselling and testing in a black township in Cape Town, South Africa. *Sexually Transmitted Infections.* (79):422-447.

Kalichman, Seth C., Leickness C. Simbayi, Demetria Cain, Sean Jooste, Donald Skinner, and Charsey Cherry. 2006. Generalizing a model of health behaviour change and AIDS stigma for use with sexually transmitted infection clinic patients in Cape Town, South Africa. *AIDS Care.* 18(3):178-182.

Kebaabetswe, Poloko, and Kathleen F. Norr. 2002. Behavioural Change: Goals and Means. In *AIDS in Africa*, edited by Max Essex, Souleymane Mboup, Phyllis Kanki, Richard Marlink and Tlou Shelia D. pp. 514-526. New York: Kluwer Academic/Plenum.

Kenyon, Kristi. 2005. Routine HIV Testing: A View from Botswana. *Health and Human Rights.* 8(2):21-23.

Kippax, Susan. 2006. A public health dilemma: A testing question. *AIDS Care.* 18(3):230-235.

Kleinman, Arthur. 1980. *Patients and Healers in the Context of Culture: An Exploration of the Borderland between Anthropology, Medicine, and Psychiatry.* Berkley: University of California Press.

Kleinman, Arthur. 1988. *The Illness Narratives: Suffering, Healing, and the Human Condition.* The United States of America: Basic Books, A Division of Harper Collins Publishers.

Leclerc-Madlala, Suzanne. 1997. Infect One, Infect All: Zulu Youth Response to the AIDS Epidemic in South Africa. *Medical Anthropology.* 17:367-380.

Leclerc-Madlala, Suzanne. 2005. Popular Responses to HIV/AIDS and Policy. *Journal of Southern African Studies.* 31(4):845-856.

loveLife. 2004. *loveLife 2004 Report on Activities and Progress.* Parklands, South Africa: loveLife.

Macklin, Ruth. 2005. Scaling Up HIV Testing: Ethical Issues. *Health and Human Rights.* 8(2):27-30.

Mahar, Cheleen, Richard Harker, and Chris Wilkes. 1990. The Basic Theoretical Position. In *An Introduction to the Work of Pierre Bourdieu*, edited by Richard Harker, Cheleen Mahar, and Chris Wilkes. pp. 1-26. Houndsmills: The Macmillian Press Ltd.

Mann, Jonathan M., Sofia Gruskin, Michael A. Grodin, and George J. Annas, Eds. 1999. *Health and Human Rights: A Reader.* New York: Routledge.

Mathews, Catherine. 2005. Reducing sexual risk behaviours: Theory and research, successes and challenges. In *HIV/AIDS in South Africa*, edited by S.S. Abdool Karim and Q. Abdool Karim. pp.143-165. Cambridge: Cambridge University Press.

Matovu, Joseph K.B. and Fredrick E. Makumbi. 2007. Expanding access to voluntary HIV counselling and testing in sub-Saharan Africa: alternative approaches for improving uptake, 2001–2007. *Tropical Medicine and International Health.* 12(11):1315-1322.

Merson, Micheal H. 2006. The HIV-AIDS Pandemic at 25 - The Global Response. *New England Medical Journal.* 354(23):2414-2417.

Mfundisi, Coceka, Nirasha Chiranjan, Charl Rodrigues, Launel Kirchener, Peter Bock, and Landon Myer. 2005. Availability of antiretroviral therapy is associated with increased uptake of HIV testing services. *South African Medical Journal.* 85(7):483-485.

Mgcobo, Mabutho. 2007. Some prefer death over testing. *health-e.* September 27, 2007. Available at: www.health-e.org.za (Accessed 27 September 2007).

Nachega, Jean B., Dara A. Lehman, Dorothy Hlatshwayo, Rachel Mothopeng, Richard E. Chaisson, and Alan S. Karstaedt. 2005. HIV/AIDS and Antiretroviral Treatment Knowledge, Attitudes, Beliefs, and Practices in HIV-Infected Adults in Soweto, South Africa. *Journal of Acquired Immune Deficiency Syndromes.* 38(2):196-201.

Nascimento-Schulze, Clelia, Ygor Fontes Garcia, and Daisy Costa Arruda. 1995. Health Paradigms, Social Representations of Health and Illness and Their Central Nucleus. *Papers on Social Representations.* 4(2):1-12.

Nattrass, Nicoli. 2003. Highly Active Antiretroviral Therapy and Risky Sex: Is There A Link? In *Centre for Social Science Research Working Paper No. 40.* Cape Town: Centre for Social Science Research, University of Cape Town.

Nattrass, Nicoli. 2007. *Mortal Combat: AIDS Denialism and the Struggle for Antiretrovirals in South Africa.* Scottsville: University of KwaZulu Natal Press.

Parker, Richard and Peter Aggleton. 2003. HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Social Science & Medicine.* 57:13-24.

Parsons, Talcott. 1975. The Sick Role and the Role of the Physician Reconsidered. *The Milbank Memorial Fund Quarterly, Health and Society.* 53(3):257-278.

PBS Frontline. 2007. *The Age of AIDS.* [Movie]. Available at: http://www.pbs.org/wgbh/pages/frontline/aids/

Postone, Moishe, Edward LiPuma, and Craig Calhoun. 1993. Introduction: Bourdieu and Social Theory." In *Bourdieu: Critical Perspectives*, edited by Craig Calhoun, Edward LiPuma, and Moishe Postone. pp.1-13. Cambridge: Policy Press in association with Blackwell Publishers.

Pronyk, P. M., J. C. Kim, M. B. Makhubele, J. R. Hargreaves, R. Mohlala, and H. P. Hausler. 2002. Introduction of voluntary counselling and rapid testing for HIV in rural South Africa: from theory to practice. *AIDS Care.* 14(6):859-865.

Putnam, Robert D. 2000. Bowling Alone: The collapse and revival of the American community. New York: Simon & Schuster.

Robins, Steven. 2006. From "Rights" to "Ritual": AIDS Activism in South Africa. *American Anthropologist.* 108(2):312-323.

Shisana, O, et al. 2005. *South African National HIV Prevalence, HIV Incidence, Communication and Behaviour Survey, 2005.* Cape Town: HSRC Press.

Simbayi, Leickness C., Seth Kalichman, Anna Strebel, Allanise Cloete, Nomvo Henda, Ayanda Mqeketo. 2007. Internalized stigma, discrimination, and depression among men and women living with HIV/AIDS in Cape Town, South Africa. *Social Science & Medicine.* 64:1823-1831.

Skhosana, Nokuthula L., Helen Struthers, Glenda E. Gray, and James A. McIntyre. 2006. HIV disclosure and other factors that impact on adherence to antiretroviral therapy: the case of Soweto, South Africa. *African Journal of AIDS Research.* 5(1):17-26.

Smith, Brian N. and Mark F. Stasson. 2000. A Comparison of Health Behavior Constructs: Social Pscyhology predictors of AIDS-Preventive Behaviorial Intentions. *Journal of Applied Social Psychology.* 30(3):443-462.

Sontag, Susan. 1978. *Illness as Metaphor.* New York: Farrar, Straus & Giroux.

Sontag, Susan. 1989. *AIDS and its Metaphors.* New York: Farrar, Straus & Giroux.

SoulCity. 2008. Welcome to the Soul City Institute Website. *Soul City Institute Health and Development Communication.* Available at: http://www.soulcity.org.za/ (Accessed 26 January 2008).

South African National AIDS Council (SANAC). 2007. *HIV/AIDS & STI National Strategic Plan 2007-2011.* Pretoria: Department of Health.

Sweat, Michael, Steven Gregorich, Gloria Sangiwa, Colin Furlonge, Donald Balmer, Claudes Kamenga, Olga Grinstead, and Thomas Coates. 2000. Cost-effectiveness of voluntary HIV-1 counselling and testing in reducing sexual transmission of HIV in Kenya and Tanzania. *Lancet.* 356:113-121.

Tarantola, David. 2005. HIV Testing: Breaking the Deadly Cycle. *Health and Human Rights.* 8(2):37-41

UNAIDS. 2006a. *2006 Report on the Global AIDS Epidemic.* Geneva: UNAIDS.

UNAIDS. 2006b. *AIDS Epidemic Update.* Geneva: UNAIDS.

UNAIDS. 2007. *AIDS Epidemic Update.* Geneva: UNAIDS.

UNAIDS Reference Group on HIV/AIDS and Human Rights. 2005. Ensuring a Rights-Based Approach to HIV Testing. *Health and Human Rights.* 8(2): 43-44.

UNAIDS/WHO. 2006. UNAIDS/WHO Policy Statement on HIV Testing. Available at: http://www.who.int/rpc/research_ethics/hivtestingpolicy_en_pdf.pdf (Accessed 4 December 2007).

Voluntary HIV-1 Counseling and Testing Efficacy Study Group. 2000. Efficacy of voluntary HIV-1 counselling and testing in individuals and couples in Kenya, Tanzania, and Trinidad: a randomised trial. *The Lancet.* 356:103-112.

Weiser, Sheri D., Michele Heisler, et al. 2006. Routine HIV Testing in Botswana: A Population-Based Study on Attitudes, Practices, and Human Rights Concerns. *PLos Medicine.* 3(7):1013-1022.

Western Cape Education Department. 2002. *WCED HIV/AIDS Life Skills Programme.* November 30, 2002. Available at: http://wced.wcape.gov.za/planning&devel/support/special_ed/hiv_aids/info_2003.html#2 (Accessed 28 January 2008).

WHO/UNAIDS. 2007. *Guidance on provider-initiated HIV testing and counselling in health facilities.* Switzerland : WHO Press.

Williams, Simon J. 1995. Theorising class, health and lifestyles: can Bourdieu help us? *Sociology of Health & Illness.* 17(5):57-64.

Wood, Robin. 2005. Antiretroviral therapy. In *HIV/AIDS in South Africa*, edited by S.S. Abdool Karim and Q. Abdool Karim. pp.504-523. Cambridge: Cambridge University Press.

Young, J.T. 2004. Illness behaviour: a selective review and synthesis. *Sociology of Health & Illness.* 26:1-31.

Appendices

Appendix 1 – Interview Guide

The Questions:

The questions below should not be followed directly. This outline provides a general structure and can be used to track what information has been spoken about and what still needs to be discussed. Sometimes tangents lead to very interesting and valuable information that was not predicted in the outline. Go with these tangents! Also, allow for silences. Do not fill in all open space with chatter because some people need time to think over a question.

AIDS and HIV

- What is HIV? What is AIDS?
- What do these things make you feel like?
- How do other people feel about HIV or AIDS?
- What are some things people say about HIV and AIDS?
- Are there other words for HIV or AIDS?
- Does having HIV change anything about you? What about having AIDS?
- What happens when you have HIV? AIDS?

Fear/discrimination

- How are people with HIV or AIDS treated?
- Who treats them this way?
- What are feelings associated with people who are HIV-positive or living with AIDS?
- Are these positive or negative feelings?
- Where do you go for support?
- Who can you talk to about HIV or AIDS?

Sources of Information

- Where and when did you first hear about HIV/AIDS?
- Where do you get information about it now?
- Do you talk about it with you family? Your friends?
- How do you feel about HIV/AIDS now? Have your feelings changed?
- What has influenced this change?

Testing

- How would you know if you were HIV positive?
- Where can you get tested?
- Is it easy to do?
- How much does it cost?
- What are reasons to get tested?
- What are reasons why you would not get tested?
- What happens once you have been tested?
- Has anyone you know ever been tested for HIV?
- Have you ever been tested for HIV?
- What was that like?

Disclosure

- If someone finds out that he or she is HIV positive, does this person have to tell anyone?
- What happens if this person does tell someone?
- What happens if he or she doesn't?
- Can other people know that someone is HIV positive even if that person hasn't told anyone?
- How do these people still find out?
- Are there risks to disclosing that you are HIV positive?
- Are there benefits?

Treatment

- What is a treatment?
- Where do treatments come from?
- What are some treatments for illnesses?

- Does HIV need to be treated? Does AIDS?
- How do you treat it?
- Is there a treatment that can be used for AIDS?
- What do these treatments do?
- Do all treatments work?
- Where do you find out about treatments?

ARVS

- What does "ARV" mean? What about HAART? Or ART?
- Where do ARVs come from?
- Who takes ARVs?
- How do you use/take ARVs?
- Do ARVs work?
- How/why do they work/not work?
- Have you ever seen ARVs before?
- Do you know the names of any ARVs?
- Can you stop taking ARVs?

Locally specific

- Are ARVs available in this area?
- How would someone get ARVs if they wanted them?
- How much do they cost?
- Is it easy to start taking ARVs?
- Do any people in this area take ARVs?
- Have you met someone who takes ARVs?

Benefits and Risks of ARVs

- Are there good reasons to take ARVs?
- What are they?
- Are there any down sides to taking ARVs?
- What are the down sides?
- What is a side effect?
- Are any of those associated with ARVs?
- Where do you hear about side effects from? (doctors versus people on ARVs)
- Who do you trust with this information?
- Do the risks out weigh the benefits of ARVs?
- Or do the benefits make them worth while?

Impacts of Treatment

- How long have you know about ARVs?
- Where did you first hear about them?
- Where are they spoken about now?
- Do people talk about ARVs?
- Who?
- How did you feel about ARVs when you first heard about them?
- How do you feel about them now?
- Did your feelings about HIV or AIDS change when you learned about ARVs?

Additionally, all participants were asked to discuss the following topics about their own testing behaviour:

1. How did you feel before getting tested for HIV?
2. How did you feel after testing for HIV but before getting your results?
3. How did you feel after you had gotten you test results?
4. Can you offer suggestions that would help to encourage other people to get tested for HIV?

Appendix 2 – Maps

Figure 1 illustrates the distance between the townships of Nyanga (green arrow) and Khayelitsha (red arrow). The map in Figure 2 shows the distance between Cape Town and the Eastern Cape. The hometowns of the participants are marked with arrows. Maps were obtained from Google Maps 2008.

Figure 1: Map of Cape Town Metropolitan Area

Figure 2: Map of Western and Eastern Cape provinces

Appendix 3 – Informed Consent

The initial intentions of research were to explore the links between expanded ARV treatment access and increased uptake of voluntary HIV testing. These intentions were adapted during the study to produce the findings presented in this thesis. The original informed consent form has been reproduced below.

An exploration into the level and impact of AIDS treatment literacy on HIV testing among young people in South Africa

Thank you for agreeing to be interviewed for this research project. This research is being conducted for the completion of a Master's dissertation in HIV/AIDS and Society through the University of Cape Town and aims to contribute towards a greater understanding of the level and impacts of knowledge about HAART.

What is the purpose of the study?
This research is being done to assess the level, type, sources, and impacts of knowledge regarding AIDS treatments. The interview asks about your understanding of AIDS treatment options, and more specifically HAART, and seeks to find how this information impacts perceptions and reactions to the epidemic. The outcomes of this research have the potential of impacting choices around treatment literacy programs in the future.

Do I have to participate?
Your participation in this study is voluntary. Should you agree to participate, you are required to sign this form. You are free to withdraw from the study at any stage, and you may also skip any particular question, or questions, if you do not wish to answer them.

Will the information be treated confidentially?
All of the information that you give us will be treated confidentially. No information which could identify you or your household will ever be released.

How will the information be used?
The interview will be recorded, transcribed and translated for research and writing purposes. The tapes will not be made available to anyone. Please inform the researcher if there is any information that you do not want to be used in the writing phase of this project.

Contact details:
If you have questions about this interview contact Hannah Lane at 082 793 8832.

I, ... (name of respondent in block letters) have read and understood all the information given to me about my participation in this study and I was given the opportunity to discuss it and ask questions. I volunteer to take part in this study. I have received a copy of this consent form.

_____ _____

(Signature) (Date)